

## Nebraska Law Review

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Volume 95 | Issue 4

Article 5

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2017

# Restoring Civil Rights to the Disabled in Health Insurance

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### Recommended Citation

Valarie K. Blake, *Restoring Civil Rights to the Disabled in Health Insurance*, 95 Neb. L. Rev. 1071 (2016)

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Valarie K. Blake\*

## Restoring Civil Rights to the Disabled in Health Insurance

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\* The author would like to thank speakers and participants of the American Society for Law, Medicine, and Ethics 2016 Annual Health Law Professor's Conference and the health law/disability law panel at the 2016 Southeastern Association of Law Schools (SEALS) conference for comments and insights on this paper. Special thanks to Jessica Roberts and Elizabeth Pendo for thoughtful comments and conversations. Thanks must also go to the members of my writing group including Atiba Ellis, Jessica Haught, and Elaine Wilson for keeping me accountable and to Josh Fershee for his support as Associate Dean of Faculty Research. Lastly, many thanks to West Virginia University College of Law and the Hodges Bloom fund for research support and to Maggie Power for research assistance. All errors and omissions are the author's own.

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## I. INTRODUCTION

Disability discrimination permeates the American health insurance system. Insurers may harm people with disabilities through their benefits designs, by limiting covered inpatient hospital days, by only covering rehabilitative services that achieve full and not partial recovery, or by excluding from coverage disability-critical services like habilitative care or durable wheelchairs. Some discrimination may be unintentional, but nonetheless harmful, for example if insurers design their health benefits with only the nondisabled in mind. Some discrimination may be purposeful as private insurers have incentives to discriminate against the disabled because of their collectively high health care consumption.<sup>1</sup>

Disability-based discrimination by health insurers is problematic for the same reasons that disability discrimination is problematic in other contexts. Adequate health benefits at affordable rates are integral to a disabled person's full participation in society.<sup>2</sup> Unchecked health insurance discrimination may undermine the admirable goals

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1. For examples of how insurers may limit services to the disabled, particularly private insurers, see Deborah A. Stone, *The Struggle for the Soul of Health Insurance*, 18 J. HEALTH POL. POL'Y & L. 287, 308 (1993) (explaining how American health care is distributed "in *inverse* relation to need, and to the large extent that commercial insurers operate on this principle, the American reliance on the private sector as its main provider of health insurance establishes a system that is perfectly and perversely designed to keep sick people away from doctors"); see Mary Crossley, *Becoming Visible: The ADA's Impact on Health Care for Persons with Disabilities*, 52 ALA. L. REV. 51, 78 (2000) (explaining how private insurers "have traditionally made it their business on a routine basis to make decisions regarding the availability and nature of benefits by taking into account individuals' health characteristics in a fashion that could often be construed as discrimination on the basis of disability"); see also Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 27 (2004) (explaining the impact of preexisting condition exclusions on people with disabilities and the adequacy of their health care coverage); see also Jessica L. Roberts, *"Healthism": A Critique of the Antidiscrimination Approach to Health Insurance and Health-Care Reform*, 2012 U. ILL. L. REV. 1159, 1166 (explaining how insurers engage "in risk-assessment and other profit-maximizing strategies that systematically disadvantage people with histories of illness and chronic health conditions").
  2. *Disability and Health*, U.S. DEP'T OF HEALTH & HUMAN SERVS., HEALTHYPEOPLE.GOV, <https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health> [https://perma.unl.edu/3W3V-LXRJ]. See also MARTHA C. NUSSBAUM, *FRONTIERS OF JUSTICE: DISABILITY, NATIONALITY, SPECIES MEMBERSHIP* (2007) (advocating for equality for the disabled for political and moral reasons).

of the disability rights movement to equalize participation by the disabled in civic and social life.<sup>3</sup> Civil rights laws for the disabled, like the Americans with Disabilities Act (ADA)<sup>4</sup> and its predecessor, the Rehabilitation Act of 1973 (Rehab Act),<sup>5</sup> have done much to improve the lives of disabled Americans in the workplace and in public life. Despite these broad advancements for the disabled, the laws have proven fruitless in combating health insurance discrimination.<sup>6</sup>

The ADA's and Rehab Act's failures in the context of health insurance can be attributed to a thirty-year-long unwillingness by the courts to consider health insurance benefits as within the scope of civil rights protections for the disabled. Beginning with the Supreme Court in *Alexander v. Choate*, courts have applied a "meaningful access" standard, holding that benefits providers need only offer people with disabilities access to their programs, but need not ensure that the programs offer the disabled comparable benefits.<sup>7</sup> In other words, antidiscrimination laws only provide people with disabilities with the ability to access a program, not the right to challenge its content. Any effort to argue for better or different benefits is viewed as a "fundamental alteration" to a program which is an affirmative defense for insurers.<sup>8</sup> Professor Samuel Bagenstos aptly dubbed this judicial reasoning framework the "access/content" distinction.<sup>9</sup> For example, a civil rights claim that a disabled person was barred from buying the same health insurance plan as others might succeed. But a claim that the benefits themselves are discriminatory in some way would not. Given this access/content distinction, insurers have an affirmative defense against any benefit changes on the basis that it fundamentally alters their programs. They need not even prove that the benefit change is too costly or burdensome, only that it involves a change to

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3. NUSSBAUM, *supra* note 2, at 15.

4. Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101–12213 (2012).

5. Rehabilitation Act of 1973 § 504, 29 U.S.C. § 794 (2012).

6. Sara Rosenbaum et al., *Civil Rights in a Changing Health Care System*, 16 HEALTH AFF. 90, 91 (1997); David Barton Smith, *Healthcare's Hidden Civil Rights Legacy*, 48 ST. LOUIS. U. L.J. 37, 45–47 (2003) (discussing the limited history of civil rights in health care).

7. *Alexander v. Choate*, 469 U.S. 287, 304 (1985).

8. Both Titles II and III of the ADA only require covered entities to make reasonable modifications to their programs. Entities are not required to make "fundamental alterations" to their programs. Fundamental alterations are seen as changes to the basic character of the good or service. For more on this, see Sara Rosenbaum, *The Americans with Disabilities Act in a Health Care Context*, in *THE FUTURE OF DISABILITY IN AMERICA* (Marilyn J. Field & Alan M. Jette eds., 2007). See also *infra* Part III for a discussion of this topic in greater detail.

9. SAMUEL R. BAGENSTOS, *LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT* 55, 71 (2009) (stating in health insurance cases, "accommodation can be required only if it provides people with disabilities 'access' to the same benefit received by nondisabled individuals; an accommodation that would alter the 'content' of the benefit will not be required").

benefits.<sup>10</sup> Thus, even modest and uncostly requests for benefit changes are beyond the reach of these laws. For these reasons, disability rights protections are completely deficient at combating benefits discrimination in health insurance.<sup>11</sup>

Importantly, the access/content distinction compromises the Rehab Act's and the ADA's accommodation mandates which form the heart of disability antidiscrimination law.<sup>12</sup> The Rehab Act and the ADA collectively recognize that reasonable accommodation in employment, transportation, public infrastructure, and other settings is necessary to fully and meaningfully integrate disabled people into society.<sup>13</sup> Unlike other antidiscrimination laws, the ADA and Rehab Act specifically recognize that treating the disabled the same as the nondisabled is simply not enough. Sometimes disabled people's unique needs have to be taken into account in order to fully integrate them into society.<sup>14</sup> Reasonable accommodation in health insurance is obviously critical: the disabled's health care needs (and broader goals of social integration) will not be met if the insurers can design their benefits to take into account only those with lesser health care needs.<sup>15</sup> However, be-

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10. BAGENSTOS, *supra* note 9, at 71 ("[A]n accommodation that would alter the 'content' of the benefit will not be required even if it can be provided at reasonable cost and without undue hardship.").
  11. Bagenstos, *supra* note 1 ("In short, the ADA has proven ineffective in challenging the limits on private health insurance for people with disabilities, and the access/content distinction has been largely responsible for that result."); *see also* Alexander Abbe, "Meaningful Access" To Health Care and the Remedies Available To Medicaid Managed Care Recipients Under the ADA and the Rehabilitation Act, 147 U. PA. L. REV. 1161, 1202 (1999) ("Choate's basic holding, that a blanket cap on health care is not a deprivation of meaningful access, has been repeatedly upheld by courts, but this holding overlooks the fact that treating the disabled and nondisabled exactly alike will not result in the same benefits for the two groups; otherwise, there would be no need for a Rehabilitation Act or an ADA.").
  12. Compare James Leonard, *The Equity Trap: How Reliance on Traditional Civil Rights Concepts Has Rendered Title I of the ADA Ineffective*, 56 CASE W. RES. L. REV. 1, 8 (2005) ("The ADA's great innovation is the adoption of an active, integrationist plan in a civil rights context . . . its principal tool is the reasonable accommodation requirement."), with Mary Crossley, *Reasonable Accommodation as Part and Parcel of the Antidiscrimination Project*, 35 RUTGERS L.J. 861, 911 (2004) (describing commentators critique of reasonable accommodation as overstepping traditional civil rights doctrine).
  13. Crossley, *supra* note 12; *see also* Leonard, *supra* note 12 (explaining that the principle tool of the ADA is the reasonable accommodation provision).
  14. Bonnie Poitras Tucker, *The ADA's Revolving Door: Inherent Flaws in the Civil Rights Paradigm*, 62 OHIO ST. L.J. 335, 344 (2001) ("[T]he ADA requires different treatment for people with disabilities. The ADA gives recognition to the incontrovertible fact that to provide individuals with disabilities with equal opportunities the civil rights model must be amended or expanded to incorporate the concept of accommodations.").
  15. Sara Rosenbaum, *Insurance Discrimination on the Basis of Health Status: An Overview of Discrimination Practices, Federal Law, and Federal Reform Options*,

cause of the access/content distinction, reasonable accommodation in health insurance has been starkly absent.

The Patient Protection and Affordable Care Act (ACA) focused on eradicating discrimination in health insurance particularly against the unhealthy and these efforts can indirectly help the disabled who collectively consume higher amounts of health care. But, to the extent that the ACA still allows for some disability-based discrimination (and to the extent that measures against health status discrimination set in motion by the ACA are repealed or no longer stand in the future), civil rights attempts will prove important. But such efforts are doomed to failure so long as the access/content distinction stands. This Article argues that the access/content divide is no longer good law and courts should no longer use it to bar suits against insurers by the disabled. A variety of practical, legal, and regulatory changes to our health care legal system have overturned the access/content divide or, at the very least, have rendered it dangerously outdated. Courts must consider a new approach to handling health insurance discrimination against the disabled.

One reason to move past the access/content divide is the agency that manages discrimination in health care, the Department of Health and Human Services Office of Civil Rights (DHHS/OCR), has attempted to look past this divide in its attending rules for section 1557, the civil rights provision of the ACA, which prohibits discrimination on the basis of race, sex, age, and disabilities by health care entities.<sup>16</sup> This law suggests a new vision of equality in health benefits<sup>17</sup> that goes beyond the doctrine of *Choate*. In reading section 1557 with other provisions of the ACA, it is clear that DHHS/OCR and even Congress have made health benefits fair game for civil rights and antidiscrimination law, effectively overriding *Choate*. Another reason is that, in considering the rationales for the access/content distinction first articulated by *Choate*, it's very clear that they no longer hold weight in a post-ACA health care world and may be bad precedent for courts to uphold.

The Article proceeds in four parts. Part II begins with a discussion of the particular importance of health benefits for people with disabilities. It details why health insurance is so critical to the disabled as a population, why the disabled tend to be discriminated against by insurers, what has been done about this so far through the ACA, and where discrimination persists post-ACA. Part III explains the *Choate* Court's reasoning in creating the access/content distinction and its im-

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37 J.L. MED. & ETHICS, no. 3, Fall 2009, at 114–15 (special supplement to issue 3).

16. Patient Protection and Affordable Care Act, 42 U.S.C. § 18116(a) (2012).

17. Valarie K. Blake, *An Opening for Civil Rights in Health Insurance After the Affordable Care Act*, 36 B.C. J. L. & Soc. JUST. 235, 261 (2016).

plications for disability civil rights claims in health insurance. Part IV argues that the access/content standard created by *Choate* should be reconsidered in light of a new regulatory environment driven by Congress through the ACA, and particularly by DHHS/OCR through its section 1557 regulations. Finally, Part V proposes that disability-based health benefits discrimination challenges be considered by the courts and by DHHS/OCR and that reasonable accommodation be the standard for addressing inequities. The Article ultimately challenges the notion that health insurance benefits are immune from antidiscrimination law and argues that it is legally and practically necessary to reintroduce disability antidiscrimination law into health insurance.

## II. THE DISABLED, HEALTH INSURANCE, AND BENEFITS DISCRIMINATION

The disabled collectively have greater and sometimes unique health care needs when compared to the nondisabled. While this is not true for all disabled people, many need health services in order to fully integrate into society.

The Affordable Care Act has improved the climate of health care financing for everyone, including the disabled, but some discrimination remains. This section will highlight the importance of health care benefits for the disabled and areas where discrimination in health insurance persists, informing why civil rights for the disabled are critical in the health insurance context.

### A. The Relationship Between Medical Need and Disability

Before discussing the particular medical needs of the disabled, it is important to define what it means to have a disability. In 2010, 56.7 million Americans had a disability, making up almost 20% of our civilian population.<sup>18</sup> The term “disabled” can have varying social, medical, or political definitions. For this paper, I adopt the standard legal definition found in the ADA and the Rehab Act. There, disability is defined by having a physical or mental impairment that affects a major life activity, such as walking, eating, drinking, or leaving the home.<sup>19</sup> Disabilities can be physical, mental, or both.<sup>20</sup> While disabil-

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18. Press Release, U.S. Census Bureau, 25th Anniversary of the Americans with Disabilities Act (May 28, 2015), <https://www.census.gov/newsroom/facts-for-features/2015/cb15-ff10.html> [<https://perma.unl.edu/P3TQ-Z6A9>]

19. This also broadly captures people who are perceived by others as having such a disability or who have a record or history of a disability. Americans with Disabilities Amendments Act of 2008, 42 U.S.C. § 12102 (2012).

20. In a Kaiser Family Foundation survey of 1505 disabled adults aged 18–64, 61% of disabled reported having a physical disability, 15% had a mental disability, and 24% had both. KRISTINA HANSON ET AL., KAISER FAMILY FOUND., UNDERSTANDING THE HEALTHCARE NEEDS AND EXPERIENCES OF PEOPLE WITH DISABILITIES: FIND-

ity can be congenital, for example being born blind, most disabilities occur in adult years from accident or illness, for example an amputation that is a result of a car accident.<sup>21</sup> We are all vulnerable to disability—one in four people are disabled by retirement age<sup>22</sup> and two-thirds of people are disabled by age 85.<sup>23</sup>

Not all disabled people have significant health care needs, nor can all disabled be properly described as sick. Take a person with a movement disability, like quadriplegia, and ask yourself whether you would view them as sick, though they may need some medical services to accommodate their disability.<sup>24</sup>

Yet, the disabled collectively are in poorer health and consume more health care resources than the nondisabled.<sup>25</sup> They are four times more likely to report fair or poor health,<sup>26</sup> and are at much greater risk than the general population of acquiring a host of chronic diseases.<sup>27</sup>

Disabled persons may sometimes simply have greater and more expensive medical needs because of their disability. For example, a per-

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INGS FROM A 2003 SURVEY (2003), <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/understanding-the-health-care-needs-and-experiences-of-people-with-disabilities-findings-from-a-2003-survey.pdf> [https://perma.unl.edu/ZM83-Q8AQ]

21. *Id.* (finding a vast majority (80%) became disabled later in life, while 9% were born with a disability or acquired it before age one, and a remaining 10% were disabled before age eighteen).
22. SOC. SEC. ADMIN., THE FACTS ABOUT SOCIAL SECURITY'S DISABILITY PROGRAM (2017), <https://www.ssa.gov/disabilityfacts/materials/pdf/factsheet.pdf> [https://perma.unl.edu/S455-YYTY]
23. Gloria L. Krahn et al., *Persons with Disabilities as an Unrecognized Health Disparity Population*, 105 AM. J. PUB. HEALTH S198, S200 (2015).
24. Susan Wendell has captured this relationship between chronic disease and other disabilities, providing labels of "healthy" disabled and "unhealthy" disabled, to recognize that not all disabled people can be considered sick or vice versa. According to Wendell, healthy disabled are people with static physical conditions or functional limitations who don't face greater or more immediate mortality than their nondisabled counterparts. Unhealthy disabled may be more dependent on medical care maintain their well-being and may face acute or chronic illness that can contribute to disability and functional impairment. Susan Wendell, *Unhealthy Disabled: Treating Chronic Illnesses as Disabilities*, 16 Hypatia, Fall 2001, at 17.
25. Nancy Sharby et al., *Decreasing Health Disparities for People with Disabilities Through Improved Communication Strategies and Awareness*, 12 INT'L J. ENVT'L. RES. & PUB. HEALTH 3301 (2015).
26. Krahn et al., *supra* note 23, at S198.
27. Disabled people are about four times as likely to have heart disease. They are also more likely to be diagnosed with diabetes. Krahn, *supra* note 23, at S201. For more general information on health disparities in disabled populations, see Michael Ulrich, *Challenges for People with Disabilities Within the Health Care Safety Net*, HEALTH AFF. BLOG (Nov. 18, 2014), <http://healthaffairs.org/blog/2014/11/18/challenges-for-people-with-disabilities-within-the-health-care-safety-net/> [https://perma.unl.edu/VCQ8-76CA].



son with Multiple Sclerosis may need regular medical check-ups but also treatment for a variety of symptoms that are a consequence of that disease, like bladder problems, dizziness, or pain. And disabled people may not just need more care, but different care. For example, some disabled people require auxiliary aids to interface with the health care system and the public, which are unique to their conditions and not required by the nondisabled.<sup>28</sup>

Some of disabled people's greater medical need may be attributable to poor access to social determinants of good health, or the social conditions that create and sustain a healthy life.<sup>29</sup> For example, disabled people are less financially secure and are about twice as likely as others to be unemployed.<sup>30</sup> They are also less likely to have a high school education, or access to internet or adequate transportation.<sup>31</sup> They are more likely to be victims of violent crime and to have inadequate social and emotional support.<sup>32</sup> These social conditions are attributed with poorer health outcomes for disabled and nondisabled alike. In addition, social conditions may make the disabled more likely to engage in health behaviors that can be harmful to their health. For example, the disabled are about 1.5 times more likely to smoke and to be obese and to not participate in physical activity for leisure.<sup>33</sup>

These medical and social conditions contribute to a greater need for health care and thus health insurance on the part of the disabled.

## B. Health Insurance and the Disabled

Despite their greater need for medical care and the importance of that care to integrating the disabled into society, disabled people face profound challenges with accessing the health care system, both in facing frequent discrimination in health care delivery<sup>34</sup> and—the fo-

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28. For examples of common barriers that disabled people face, see *Common Barriers to Participation Experience by People with Disabilities*, CTRS. FOR DISEASE CONTROL & PREVENTION (Mar. 17, 2016) [hereinafter *Common Barriers to Participation*], <http://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html> [https://perma.unl.edu/LRY5-YVLU].

29. *The Social Determinants of Health: Know What Affects Health*, CTRS. FOR DISEASE CONTROL & PREVENTION (Oct. 13, 2016), <https://www.cdc.gov/socialdeterminants/> [https://perma.unl.edu/7SHR-DYNG].

30. *Id.*

31. Krahn et al., *supra* note 23, at S201.

32. *Id.*

33. These can be a direct result of social barriers to health that the disabled face. For example, a double amputee may have a difficult time finding suitable gym equipment to help her participate in cardiovascular exercise. Ulrich, *supra* note 27; see also *Common Barriers to Participation*, *supra* note 28 (noting seven common barriers to social and physical participation that individuals with disabilities face).

34. While this Article will focus on health care financing and discrimination, the importance of discrimination in health care delivery should not go unmentioned. As

cus of this paper—in obtaining affordable and adequate health care benefits. The disabled are twice as likely as the nondisabled to not be able to access necessary medical care because of cost,<sup>35</sup> and they are more likely to report higher out of pocket expenses.<sup>36</sup> Disabled persons are also less likely to receive adequate preventive health care, meaning that they may not receive care until conditions are more serious and more difficult and expensive to treat.<sup>37</sup>

Insurance discrimination takes two primary forms: discrimination in who can access insurance and discrimination in what benefits (or content) they receive.<sup>38</sup> Access-based discrimination occurs at the point of purchase by making distinctions in who can or cannot gain

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the Institute of Medicine's infamous report on discrimination in health care reminds us, provider discrimination is also a significant contributor to health care disparities. *Unequal Treatment: What Healthcare Providers Need to Know About Racial and Ethnic Disparities in Healthcare*, INST. MED. (Mar. 2002), [https://www.nap.edu/html/10260/disparities\\_providers.pdf](https://www.nap.edu/html/10260/disparities_providers.pdf). Professor Elizabeth Pendo has written extensively on discrimination in health care delivery against the disabled. In studying access to reproductive technology for disabled women, for example, she uncovered barriers to basic care in the form of “inaccessible tables, chairs, scales, and mammography equipment.” Elizabeth Pendo, *Shifting the Conversation: Disability, Disparities and Health Care Reform*, 6 FIU L. REV. 87 (2010) [hereinafter Pendo, *Shifting the Conversation*]. See also Elizabeth Pendo, *Disability, Equipment Barriers, and Women's Health: Using the ADA to Provide Meaningful Access*, 2 ST. LOUIS U. J. HEALTH L. & POL'Y 15 (2008) (noting that those with disabilities receive less education and health care than those without). Others have written on potential rationing of care against the disabled by providers who view care as medically futile, when it does not achieve a level of medical benefit of the same degree as for the nondisabled. Mary Crossley, *Medical Futility and Disability Discrimination*, 81 IOWA L. REV. 179 (1995); see also David Orentlicher, *Destructuring Disability, Rationing of Healthcare and Unfair Discrimination Against the Sick*, 31 HARV. C.R.-C.L. L. REV. 49 (1996) (suggesting two possible ways of rationing health care that would have the least discriminatory effect on the disabled).

35. *Common Barriers to Participation*, *supra* note 28.

36. In all fifty states, the disabled report cost as a barrier to care more frequently than the nondisabled. *Common Barriers to Participation*, *supra* note 28. For more information, see Nancy A. Miller et al., *The Relation Between Health Insurance and Health Care Disparities Among Adults with Disabilities*, 104 AM. J. PUB. HEALTH e85 (2014).

37. For example, disabled women have been shown to receive less preventive health care and cancer screening, like mammograms and cervical cancer screenings. Krahn et al., *supra* note 23, at S198. This can be in part due to insurance coverage and also do to structural barriers in the health care setting. Pendo, *Shifting the Conversation*, *supra* note 36.

38. Rosenbaum, *supra* note 15, at 109–11 (providing examples of access-level discrimination and content-level discrimination). Professor Rosenbaum also identifies a third level, micro-level discrimination, or discrimination at the level of an individual's claim for health care. We will not focus on micro-level discrimination in this Article. Also for general background on insurance discrimination at access and content levels, see Mary Crossley, *Discrimination Against the Unhealthy in Health Insurance*, 54 U. KAN. L. REV. 73, 80 (2005).

entry to an insurance plan.<sup>39</sup> For example, an insurer might refuse or disincentive the enrollment of a person with significant disabilities into a given insurance plan.<sup>40</sup> In content-level discrimination, the disabled person is allowed to purchase the insurance, but they are treated differently in what benefits they receive.<sup>41</sup> For example, disability-specific benefits might be excluded from coverage, or there might be annual limits that disabled people need to go over.<sup>42</sup>

These limits in health insurance at the access and content levels may be equally harmful to disabled persons' health but they may also often be necessary to control health care spending, whether in private or public insurance.<sup>43</sup> Only sometimes will these actions be unlawful from a civil rights perspective.<sup>44</sup> This Article does not seek to formally define which counts as unlawful health insurance discrimination against the disabled under civil rights law. Instead, it underscores the fact that courts have not been recognizing content-level discrimination, while they do consider access-level discrimination, despite both being equally problematic to disabled people's health (and both being a vehicle in which insurers can and do control for health care costs).<sup>45</sup> It advocates for courts viewing both types of discrimination within the purview of disability antidiscrimination law.<sup>46</sup> This next section describes how health insurance discrimination against the disabled takes shape in both public and private settings.

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39. Rosenbaum, *supra* note 15.

40. *Id.*

41. *Id.*

42. *Id.*

43. Though U.S. health expenditures have slowed, the country still spends more than other countries of equal economic development and without evidence of better health outcomes. THE COMMONWEALTH FUND, U.S. HEALTHCARE FROM A GLOBAL PERSPECTIVE: SPENDING, USE OF SERVICES, AND HEALTH IN 13 COUNTRIES, [http://www.commonwealthfund.org/~media/files/publications/issue-brief/2015/oct/1819\\_squires\\_us\\_hlt\\_care\\_global\\_perspective\\_oecd\\_intl\\_brief\\_v\\_3.pdf](http://www.commonwealthfund.org/~media/files/publications/issue-brief/2015/oct/1819_squires_us_hlt_care_global_perspective_oecd_intl_brief_v_3.pdf) [<https://perma.unl.edu/6NP5-4R2W>]; see *Medicaid Managed Care for People with Disabilities*, NAT'L COUNCIL ON DISABILITY (Mar. 18, 2013), <http://www.ncd.gov/publications/2013/20130315/> [<https://perma.unl.edu/M2UU-58GP>] (discussing how public expenditure cuts in health care can particularly disenfranchise the disabled).

44. In using the term health insurance discrimination, however, I do not mean to suggest that all conduct on the part of insurers is unlawful or unethical, or even violates antidiscrimination law. Instead, I simply mean to suggest that disabled people are sometimes treated differently as a class than the nondisabled in insurance. Crossley, *supra* note 38, at 80 (acknowledging that only certain forms of health insurance discrimination would violate civil rights laws).

45. BAGENSTOS, *supra* note 9 (explaining how the courts draw a doctrinal distinction between access to benefits and content of benefits, allowing insurers to discriminate in health insurance in their benefit design).

46. For an excellent discussion of the normative considerations surrounding insurance discrimination, see Jessica L. Roberts & Elizabeth Weeks Leonard, *What Is (and Isn't) Healthism?*, 50 GA. L. REV. 833 (2016).

### 1. Public Insurance

About 50% of the disabled population has a form of public health insurance, such as Medicare or Medicaid.<sup>47</sup>

Medicaid is the first line of defense for the disabled in health insurance.<sup>48</sup> Medicaid is available to disabled persons either because they have low incomes or because they cannot work and qualify for Supplemental Security Income (SSI) benefits.<sup>49</sup> The ACA expanded Medicaid, broadening the group of disabled who may be eligible to any adult who makes below 133% of the federal poverty line (FPL).<sup>50</sup> The Supreme Court made the expansion optional for the states in *National Federation of Independent Business v. Sebelius*.<sup>51</sup> Several studies suggest that the chronically ill and low-income persons with health problems experienced the greatest increase in insurance coverage from the Medicaid expansion.<sup>52</sup> Medicare also covers some disabled if they are either over age of sixty-five, or under the age of sixty-five but cannot work and qualify for Social Security disability (SSD) benefits.<sup>53</sup>

Public insurers are unlikely to engage in access-based discrimination in regards to who is eligible to enroll, since eligibility is statuto-

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47. Miller et al., *supra* note 36.

48. Dee Mahan et al., *Cutting Medicaid: Harming Seniors and People with Disabilities Who Need Long-Term Care*, FAMILIES USA (May 2011), <http://familiesusa.org/product/cutting-medicaid-harming-seniors-and-people-disabilities-who-need-long-term-care> [https://perma.unl.edu/SP7S-8HZL] (describing in particular why Medicaid coverage is uniquely important for disabled populations).

49. Other “worthy poor” are also covered including certain children, women, some parents from low income homes, and elderly with low income who can qualify for Medicare and Medicaid (dual-eligibles). Mary Beth Musumeci, *The Affordable Care Act’s Impact on Medicaid Eligibility, Enrollment, and Benefits for People with Disabilities*, KAISER FAMILY FOUND. (Apr. 8, 2014), <http://kff.org/health-reform/issue-brief/the-affordable-care-acts-impact-on-medicaid-eligibility-enrollment-and-benefits-for-people-with-disabilities/> [https://perma.unl.edu/F9PB-U5DQ].

50. *Id.*

51. Nat’l Fed’n of Indep. Bus. v. Sebelius, 132 S. Ct. 2566 (2012). To date, thirty-two states, including Washington D.C., have expanded Medicaid. *Status of State Action on the Medicaid Expansion Decision*, KAISER FAMILY FOUND. (July 7, 2016), <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/> [https://perma.unl.edu/75PT-FWYU].

52. STEPHEN LINDER ET AL., URBAN INST., *THE IMPACT OF THE AFFORDABLE CARE ACT ON PEOPLE WITH DISABILITIES: A 2015 STATUS REPORT* (2016), [http://www.urban.org/research/publication/impact-affordable-care-act-people-disabilities-2015-status-report/view/full\\_report](http://www.urban.org/research/publication/impact-affordable-care-act-people-disabilities-2015-status-report/view/full_report) [https://perma.unl.edu/EP8E-VAR4].

53. Patients with end-stage renal disease or Lou Gehrig’s disease may also qualify for Medicare benefits. *Social Security Disability Insurance (SSDI) & Medicare Coverage*, HEALTHCARE.GOV, <https://www.healthcare.gov/people-with-disabilities/ssdi-and-medicare/> [https://perma.unl.edu/VN42-D9L6].

rily defined by income, age, or some other definable standard.<sup>54</sup> However, these insurers can sometimes engage in content discrimination by designing insurance benefits that fail to provide generous enough or specialized health benefits for the disabled.<sup>55</sup>

For example, the Medicaid benefit package is better designed for disabled populations than other insurance plans,<sup>56</sup> but even post-ACA, it does not cover some critical services like durable medical equipment, dental, and vision, and states have broad freedom to define benefits outside of a select group of mandatory benefits.<sup>57</sup> Medicaid also maintains some plans that involve managed care elements, which can be challenging for disabled people with significant health needs.<sup>58</sup> The Medicaid expansion is also limited in its ability to im-

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54. The inability of public insurers to turn away the sick and the disabled make such programs function as a safety net, especially during the time periods in which private insurers could discriminate on the basis of health status, particularly with preexisting conditions. Professor Rosenbaum demonstrates the importance of these programs because they cannot discriminate in access:

In contrast to insurance markets, Medicaid coverage is available at the very point that serious health need arises. The law contains no eligibility exclusions for pre-existing conditions; many of its numerous eligibility categories are expressly designed to deal with coverage during illness; and states are required to provide for enrollment services in health care settings in order to enable enrollment at the point of health care need.

Rosenbaum, *supra* note 15, at 104.

55. See Anita Silvers & Leslie Francis, *Human Rights, Civil Rights: Prescribing Disability Discrimination Prevention in Packaging Essential Health Benefits*, 41 J.L. MED. & ETHICS, no. 4, Winter 2013 (arguing that even public benefits can discriminate against the disabled “often on the ground that they cannot be made functional, or . . . that it is too costly to make them functional”).

56. As one interviewee in a disability activist group stated:

For people with significant disabilities, insurance just doesn’t work. Medicaid is really what you need . . . Insurance doesn’t pay for what we need. It doesn’t pay for outdoor, heavy-duty wheelchairs; it doesn’t pay for personal assistance. I guess it pays for medications, doctor visits, that kind of stuff. But the big expenses are really what people consider long-term care.

LINDER ET AL., *supra* note 52, at 29.

57. Jessica L. Roberts, *Health Law as Disability Rights Law*, 97 MINN. L. REV. 1963, 1993 (2013) (“Despite being the primary source of health insurance for people with disabilities, Medicaid has several shortcomings that contribute to the health disparities experienced by the disability community . . . beneficiaries have trouble locating health-care providers who will accept Medicaid payments . . . . Health-care professionals who serve Medicaid recipients with disabilities report impediments to providing care resulting from improper referrals and accessibility issues . . . . Additionally, Medicaid only provides limited coverage. It fails to cover many essential services, such as dental, vision, and personal assistance, as well as durable medical equipment.”).

58. Roberts, *supra* note 57, at 1993 (“Medicaid managed care programs suffer from poor coordination of care, reduced consumer choice, and a limited ability to access specialists, thereby negatively impacting health care for people with disabilities.”). See also LINDER ET AL., *supra* note 52 (explaining Medicaid administrators

prove health for disabled persons. Foremost, the true benefit cannot be reached unless all states expand.<sup>59</sup> Without expansion in all states, approximately 17.8 million people remain uninsured who could otherwise have coverage,<sup>60</sup> and the poorest in our country may not be eligible for either federal subsidies or Medicaid.<sup>61</sup> But even in states that expanded, the expansion population (with some exceptions) is not entitled to receive the same level of benefits as other previously covered Medicaid populations and instead may receive benefit packages that are more in line with private insurance (and thus not as well tailored for the disabled).<sup>62</sup> Some experts have reported less favorable insurance for disabled persons in states that have not standardized

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indicated that concern that Medicaid managed care entities “lacked experience delivering long term care for people with disabilities and that the groups would have an incentive to reduce services under a capitated rate.”).

59. Sidney D. Watson, *Embracing Justice Roberts’ New Medicaid*, 6 ST. LOUIS J. HEALTH POL’Y & L. 247, 263 (2013) (“Voluntarily expanding Medicaid and assuring that everyone has access to affordable health insurance makes sense for states. New Medicaid makes sense as a matter of public health, healthcare delivery and state finances. Most importantly, though, New Medicaid makes political sense: It creates a safety net for all and is likely to become one of the Nation’s most popular social insurance programs.”); *see also* Nicole Huberfeld & Jessica L. Roberts, *Medicaid Expansion as Completion of the Great Society*, 2014 U. ILL. L. REV. SLIP OPINIONS 1, 5–6 (2014) (“[W]hether to expand Medicaid is a social justice matter, not just an economic or political issue . . . . [W]hen the Supreme Court made Medicaid expansion optional for the States, it eroded the ACA’s primary purpose.”).
60. GENEVIEVE M. KENNEY ET AL., URBAN INST., MAKING THE MEDICAID EXPANSION AN ACA OPTION: HOW MANY LOW-INCOME AMERICANS COULD REMAIN UNINSURED (2012), <http://www.urban.org/sites/default/files/alfresco/publication-pdfs/412606-Making-the-Medicaid-Expansion-an-ACA-Option-How-Many-Low-Income-Americans-Could-Remain-Uninsured-.pdf> [<https://perma.unl.edu/8HS4-KFHM>].
61. This is a quirk in the law known as the Medicaid gap. Subsidies only apply to those within 100–400% of the federal poverty line (FPL), and Medicaid covers up to 133% only in states that expand. In states that do not expand one could have income from 0%–100% of the FPL and not be covered by either Medicaid or subsidies. Rachel Garfield & Anthony Damico, *The Coverage Gap: Uninsured Poor Adults in States That Do Not Expand Medicaid—An Update*, KAISER FAMILY FOUND. (Jan. 21, 2016), <http://kff.org/health-reform/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid-an-update/> [<https://perma.unl.edu/N83P-JDYR>].
62. Julia Paradise, *Medicaid Moving Forward*, KAISER FAMILY FOUND. (Mar. 9, 2015), <http://kff.org/health-reform/issue-brief/medicaid-moving-forward/> [<https://perma.unl.edu/7KSQ-G68F>] (“[M]ost adults in the new Medicaid expansion group receive ‘Alternative Benefit Plans’ (ABPs) . . . . Compared to traditional Medicaid benefits for adults, ABPs based on commercial insurance products may provide broader coverage of some services (e.g., behavioral health care, preventive care) and narrower coverage of other services (e.g., prescription drugs, long-term services) . . . . Certain populations must have access to all Medicaid state plan benefits, even if they are eligible for Medicaid through the new adult expansion group. They include individuals who are medically frail or have special medical needs, including people with disabling mental health disorders and complex medical conditions, dual eligible beneficiaries, and specified other beneficiary groups.”).

their Medicaid expansion benefits to match the pre-expansion packages.<sup>63</sup> Expanding Medicaid to all states could reduce some access issues, but adequacy of benefits remains an open question for both expansion and non-expansion populations.

Medicare also poses some ongoing problems for the disabled, even after the ACA. Medicare, like Medicaid, is better designed than private insurance to take into account disabled health care needs.<sup>64</sup> After all, it intentionally covers some disabled, and it is designed to tolerate costlier health care consumption, given its elderly population focus.<sup>65</sup> However, Medicare is notorious for having high out-of-pocket costs, which can differentially harm the disabled, and the ACA has only partially addressed this issue.<sup>66</sup>

## 2. Private Insurance

About 43% of disabled people use private insurance, whether in the form of employer-sponsored, small-group, or individual insurance.<sup>67</sup>

Private insurance presents a greater opportunity for disability-based and other discrimination.<sup>68</sup> Private insurers face pressure from shareholders to save money and earn profits and from consumers to keep premiums low.<sup>69</sup> Private insurers must also adjust for adverse selection, the phenomenon whereby individuals fail to purchase insurance until they know they need it, resulting in more people taking from instead of paying into the insurance pool.<sup>70</sup>

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63. LINDER ET AL., *supra* note 52.

64. Particularly this is so as public systems have been designed to accept all enrollees based on designated criteria like age or disability, and not based on risk rating.

65. Medicare is the elderly health insurance program, designed for persons over the age of sixty-five.

66. See Roberts, *supra* note 57, at 1994–95 (arguing that Medicare can be overly costly for the disabled). Some ACA provisions have tackled Medicare's cost-sharing issues, for example provisions that make cost-sharing for Medicare Part D prescription drugs less. *Closing the Coverage Gap—Medicare Prescription Drugs Are Becoming More Affordable*, U.S. DEPT OF HEALTH & HUMAN SERVS., MEDICARE.GOV, <https://www.medicare.gov/Pubs/pdf/11493.pdf> [<https://perma.unl.edu/6CGH-WPZ3>]. Additionally, low income disabled may be dual-eligible (qualifying for both Medicare and Medicaid). Medicaid then defrays some of their expenses from Medicare.

67. Miller et al., *supra* note 36, at e85.

68. See Roberts, *supra* note 57, at 1995–97 (discussing the ways that private insurance benefits can be too narrow for the disabled as a population).

69. See Crossley, *supra* note 38.

70. Tom Baker, *Containing the Promise of Insurance: Adverse Selection and Risk Classification*, 9 CONN. INS. L.J. 371, 380 (2003) (providing background on adverse selection). See also Wendy K. Mariner, *The Affordable Care Act and Health Promotion: The Role of Insurance in Defining Responsibility for Health Risks and Costs*, 50 DUQ. L. REV. 271, 280 (2012) (“Insurers in an unregulated, voluntary market segment the market by classifying risks into smaller groups. Thus, the strength of the spirit of solidarity may depend on the price of insurance and the degree to which people prefer not to be classified as a high risk.”).

Pre-ACA, private insurers were at great liberty to discriminate both in access to and content of insurance as a way of segregating the market according to risk of health care consumption and avoiding high cost consumers or shifting cost back onto them through high cost-sharing.<sup>71</sup> Any type of sickness might expose one to both access and content based discrimination, no matter how minor or severe the illness.<sup>72</sup> This was particularly felt in the small group and individual insurance markets where risk is only spread onto a few, but such discrimination could also occur in large group insurance, like employer plans.<sup>73</sup>

Access-wise, insurers could bar the entry of persons who seemed to present too great a risk to the insurer. These included people with preexisting conditions or other traits that, from an actuarial perspective, might predict high future health care consumption (for example, evidence of past health care consumption or evidence of domestic abuse).<sup>74</sup> If insurers enrolled a high-risk individual, they might offset that risk by charging higher premiums, or by terminating or refusing to renew insurance for that person the following year.<sup>75</sup>

Discriminatory benefit design was also a useful risk sorting mechanism that functioned both to shield the insurer from paying for high cost services, but also to discourage enrollment by risky consumers who were seeking more generous insurance packages.<sup>76</sup> Medical necessity reviews were one such mechanism, limiting services to only those who reach some defined level of improvement which may be unattainable for some disabled (even though they might achieve their

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71. Sara Rosenbaum et al., *Crossing the Rubicon: The Impact of the Affordable Care Act on the Content of Insurance Coverage for Persons with Disabilities*, 25 NOTRE DAME J.L. ETHICS & PUB. POL'Y 527, 532–35 (2011). Rosenbaum, *supra* note 15, at 103–04.

72. For example, Kaiser Family Foundation conducted an experiment pre-ACA in which “mock” scenarios were used to see when insurers would underwrite to exclude certain types of preexisting conditions in the individual market. Insurers denied patients, excluded coverage for conditions, and raised premiums/cost-sharing for even minor conditions like hay fever. People with more serious conditions like HIV were uninsurable and patients with costly conditions like depression had prohibitively high premiums (as much as over \$800 per month). KAREN POLLITZ, RICHARD SORIAN & KATHY THOMAS, KAISER FAMILY FOUND., HOW ACCESSIBLE IS INDIVIDUAL HEALTH INSURANCE FOR CONSUMERS LESS-THAN-PERFECT HEALTH? (2001), <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/how-accessible-is-individual-health-insurance-for-consumer-in-less-than-perfect-health-report.pdf> [<https://perma.unl.edu/X3E5-3GWD>].

73. See Crossley, *supra* note 38, at 84 (arguing that small group insurers are more likely to avoid high-risk enrollees).

74. See Stone, *supra* note 1.

75. Rosenbaum, *supra* note 38, at 106; Crossley, *supra* note 36.

76. Crossley, *supra* note 38, at 82.



own different improvement).<sup>77</sup> Insurers might also exclude or limit certain services, for example, by not covering certain rehabilitative services or by placing an annual cap on the amount of covered service.<sup>78</sup> Particularly, this was true for services that were uniquely required by disabled people and not by the general population, like auxiliary aids or wheelchairs.<sup>79</sup> The failure of insurers to cover long-term and chronic illness in favor of treating acute conditions was another mechanism.<sup>80</sup> Insurers might also exclude certain providers from their networks who serve high-risk populations<sup>81</sup> or use cost-sharing mechanisms (high deductibles, copays, and coinsurance) to penalize and discourage doctor's visits.<sup>82</sup> Professor Bagenstos views this discrimination in the private insurance market in access and benefits as not only a health care access issue for the disabled but also a significant undermining of the goals of civil rights law to integrate the disabled into the workforce.<sup>83</sup> By not being properly insurable in the private market, the disabled are forced to stop working in order to be eligible for public insurance products.<sup>84</sup>

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77. *Id.* For example, an insurer might only cover physical therapy services for patients who will recover full range of motion in their knee and fail to cover services that could make a disabled person somewhat mobile or at least comfortable when bed-bound. *See also* SARA ROSENBAUM, STATEMENT ON ESSENTIAL BENEFITS 2 (2011) (discussing medical necessity reviews as a form of insurance discrimination).

78. Orentlicher, *supra* note 34, at 54 ("Rationing by service may result in coverage for persons with a milder form of an illness while leaving those with a more severe form of the same illness uncovered.").

79. *See* Bagenstos, *supra* note 1 (discussing how an emphasis in private insurance on acute care can draw away from resources for chronic disease and long-term care needs).

80. *Id.* at 30.

81. Valarie Blake, *Narrow Networks, the Very Sick, and the Patient Protection and Affordable Care Act: Recalling the Purpose of Health Insurance and Reform*, 16 MINN. J.L. SCI. & TECH. 63, 74, 77 (2015) (arguing that failure to exclude academic medical centers that specialize in tertiary and quaternary care can be a way of avoiding the chronically ill).

82. Heavy cost-sharing has been shown to successfully reduce health care consumption, especially in low-income people, even when the services are medically necessary. RAND has specifically argued against heavy cost-sharing in modern insurance plans because they lead consumers to simply avoid health care, equally, whether medically necessary or not. *The Health Insurance Experiment: A Classic RAND Study Speaks to the Current Health Reform Debate*, RAND CORP. 4–5 (2006), [http://www.rand.org/pubs/research\\_briefs/RB9174.html](http://www.rand.org/pubs/research_briefs/RB9174.html) [<https://perma.unl.edu/5VW3-4GTK>]. *See also* Rosenbaum, *supra* note 74, at 538 (arguing that cost-sharing can be an even more effective tool to avoid health care spending than avoiding consumers based on risk-rating with premium adjustments).

83. *See* SAMUEL R. BAGENSTOS, LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT 129–30 (2009).

84. *Id.*

The ACA expanded access to private health insurance by mandating that certain employers provide insurance<sup>85</sup> and by making privately-purchased health insurance in the small group and individual markets more affordable through subsidies and tax credits for purchasers who income qualify.<sup>86</sup> The ACA also widely eliminated discrimination in private health insurance, but some opportunities for insurance discrimination remain. Private insurance is now more akin to public insurance in that access-based discrimination has largely been eradicated and most ongoing issues of discrimination or limitations occur at the level of generosity of benefits.

In terms of fighting access discrimination, private insurers must now guarantee issue<sup>87</sup> and renewability<sup>88</sup> of benefits, instead of limiting eligibility later for poor health status. Insurers also cannot deny initial enrollment in plans on the basis of a preexisting condition,<sup>89</sup> or a variety of other health-status related factors like physical or mental condition, claims history (the number of claims per patient), medical history, use of health care, genetic information, disability, or other evidence of insurability.<sup>90</sup> Insurers can only vary premiums based on a few factors (tobacco use, age, geography) and cannot vary premiums based on health-status, health consumption, or disability.<sup>91</sup> Allowing insurers to still vary premiums on the basis of tobacco use, age, and geography may contribute to ongoing health care disparities, particularly for the disabled.<sup>92</sup> While there is still some potential to discriminate in access and in premiums, for the most part we have seen great enrollment of higher risk health care consumers than previously which may further create incentives for insurers to reduce services on the benefit side.

The essential health benefits (EHBs) provision is the primary tool of the ACA to combat health benefits discrimination.<sup>93</sup> It creates ten general categories of EHBs in which insurers must cover certain services, forcing insurers to offer some level of standardized benefits to

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85. Patient Protection and Affordable Care Act § 1513, 26 U.S.C. § 4980H (2012) (imposing penalties on employers of certain sizes if they do not provide essential health services to full-time employees).

86. *Id.* §§ 1401–1402, 26 U.S.C. § 36B.

87. *Id.* § 2702, 42 U.S.C. § 300gg-1.

88. *Id.* § 2703, 42 U.S.C. § 300gg-2.

89. *See id.* § 2704, 42 U.S.C. § 1396(a).

90. *See id.* § 2705, 42 U.S.C. § 300gg-4.

91. Rates can increase threefold between ages of 18–65, and tobacco users can be charged 1.5 times more. Allowances in premiums for age, geography, and tobacco use have been criticized for perpetuating health disparities.

92. These may have a significant disparate effect on the disabled who smoke more and may frequently be older or live in lower income areas. *See Roberts, supra* note 1, at 1188.

93. Patient Protection and Affordable Care Act § 1302(b)(1), 42 U.S.C. § 18022 (2012).

enrollees regardless of their likely level of health care consumption. Of particular importance to the disabled, EHBs require coverage of mental health and substance use disorder services, prescription drugs, and rehabilitative/habilitative services.<sup>94</sup>

The statute, along with DHHS, define the broad categories of EHBs. What actually gets covered depends heavily on the individual states, which are tasked with selecting a benchmark plan that provides the baseline for coverage for all insurance plans offered on exchanges. This benchmark plan is typically the state employee plan, or a plan that reflects the highest enrollment on the small/individual group market.<sup>95</sup> All plans offered on the exchange must meet the same level of benefits as the state benchmark plan.

EHBs are subject to a nondiscrimination requirement. The Secretary of Department of Health and Human Services (DHHS) must not discriminate on the basis of “age, disability, or expected length of life”<sup>96</sup> and must consider the particular health needs of “women, children, persons with disabilities, and other groups” in establishing the EHBs.<sup>97</sup> The Secretary must also review plans periodically for whether they are preventing people from getting medical necessary care because of cost or access challenges.<sup>98</sup> There are no clear antidiscrimination rules for the States in selecting their benchmarks, however. There is some amount of uncertainty as to how broad reaching these antidiscrimination efforts are.<sup>99</sup>

The benchmark plan should cover all essential health benefits, but in practice it can still have great variation in what does or does not get covered. The plans are not necessarily thoroughly reviewed for compliance with EHB national standards and antidiscrimination standards, and why plans are picked is not always transparent. Clearly,

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94. *Id.* EHBs’ other categories include: ambulatory patient services (outpatient care), emergency care, hospitalization, maternity/pregnancy care, laboratory services, preventive and wellness services, and pediatric care including oral and vision.

95. *See State Health Insurance Mandates and the Essential Health Benefits Provision*, NAT’L CONF. OF ST. LEGISLATURES (Dec. 2015), [http://www.ncsl.org/research/health/state-ins-mandates-and-aca-essential-benefits.aspx#State\\_EHB\\_2013](http://www.ncsl.org/research/health/state-ins-mandates-and-aca-essential-benefits.aspx#State_EHB_2013) [<https://perma.unl.edu/738L-4PUG>] (providing an overview of state benchmarks).

96. *See* Patient Protection and Affordable Care Act 1302, 42 U.S.C. § 18022(b)(4)(B) (2012).

97. *See id.* § 18022(b)(4)(C).

98. *See id.* § 18022(b)(4)(G)(i).

99. *See* David D. Johnson, *Anti-Discrimination Law Comes to Health Benefit Design: Is DHHS Getting the Rules Right?*, AHLA CONNECTIONS, Nov. 2015, at 32 (asking whether discriminatory benefit designs only encompass specific measures mentioned in the rules like cost-sharing, or whether they also encompass other mechanism like narrow provider designs?). *See also* Govind Persad, *Priority Setting, Cost-Effectiveness, and the ACA*, 41 AM. J.L. & MED. 119 (2015) (asking whether discrimination in the context of EHBs still allows for medically necessity determinations).

the benchmark plan's coverage is critical.<sup>100</sup> A generous benchmark means generous benefits for all consumers, while a benchmark plans with serious gaps in coverage means these gaps will be replicated throughout the entire state. This potential for variability has been sharply criticized generally<sup>101</sup> and for its impact on the disabled specifically.<sup>102</sup> For example, stakeholders in one state's insurance exchange noted that "habilitative, mental health, and equipment services became less accessible on private insurance plans because the state chose the 'cheapest essential benefits, maybe not considering all the impacts for all consumers.'" <sup>103</sup> Another example are states that pick model plans that allow a "fail-first" coverage model, i.e., the individual can only have access to the drug after showing first that other drugs have failed.<sup>104</sup> This can be problematic for disabled populations who frequently rely on a combination of drugs.<sup>105</sup> Insurers may also continue to define medical necessity to only cover benefits that improve functioning or recover lost functioning, leaving out disabled

100. For example, see KATIE KEITH ET AL., GEORGETOWN U. HEALTH POL'Y INST., NON-DISCRIMINATION UNDER THE AFFORDABLE CARE ACT (July 2013), [https://ssa.scholars.uchicago.edu/sites/default/files/jhpl/files/nondiscriminationundertheaca\\_georgetownchir.pdf](https://ssa.scholars.uchicago.edu/sites/default/files/jhpl/files/nondiscriminationundertheaca_georgetownchir.pdf) [<https://perma.unl.edu/3C6D-THUM>] (describing how "[m]ost states did not analyze whether their essential health benefits benchmark plan included discriminatory features" while the "benchmark selection process was not transparent in many states").

101. Wendy K. Mariner, *Health Insurance is Dead; Long Live Health Insurance*, 40 AM. J.L. & MED. 195, 208 (2014) ("[V]ariation in EHB definitions can perpetuate a problem that the EHB requirement itself was intended to resolve or at least reduce—inconsistent or inadequate treatment coverage. . . . The remaining variation among the several public benefit programs and hundreds of private insurance plans can provoke complaints of unfair rationing, especially if a person who is denied treatment believes that the denial was not based on medical need, but on an insurer's profit targets."). See also Silvers & Francis, *supra* note 55 (noting concerns with plan variations).

102. Sara Rosenbaum & Joel Teitelbaum, *A Lost Opportunity for Persons with Disabilities? The Final Essential Health Benefits Rule*, HEALTH AFF. BLOG (Mar. 11, 2013), <http://healthaffairs.org/blog/2013/03/11/a-lost-opportunity-for-persons-with-disabilities-the-final-essential-health-benefits-rule/> [<https://perma.unl.edu/SZ9V-XDE9>]; see also LINDER ET AL., *supra* note 52, at 50 (discussing the variations in state benchmark plans).

103. Another state official observed:

Physical, occupational, and speech therapy: 60 visits per condition, per lifetime. That's it. And that is whether it's rehabilitation, which is regaining function, or habilitation, which would be maintaining function. Home health care: 40 visits a year. Skilled nursing: 200 days per year. Medical equipment: standard equipment only. Hearing aid: one single purchase every three years. One external prosthetic device per limb, per lifetime. God forbid you ever need a different prosthesis.

LINDER ET AL., *supra* note 52, at 37.

104. *Id.*

105. *Id.*

groups who may not reap the same definable benefit as nondisabled.<sup>106</sup>

DHHS has adjusted its final rules to address a number of coverage issues, particularly to improve access to health and substance abuse, habilitative services, and pediatric oral and vision services, suggesting that annual revisits of the rules will be necessary to monitor state compliance.<sup>107</sup> DHHS has indicated that it will allow states to select model benchmark plans into 2017 and will be reviewing the practice for how it affects enrollees.<sup>108</sup>

Ultimately, further discrimination in benefits post-ACA will be “subtle, but potent” and probably only exposed slowly through customer complaints and litigation.<sup>109</sup> For example, while insurers will no longer have direct annual or lifetime dollars limits for EHBs, they can achieve the same result others ways. The post-ACA market reflects high deductibles and high copays in many plans, which can differentially impact high consumers of health care who are more likely to need health services.<sup>110</sup> One popular practice is drug tiering, where insurers place certain specialty drugs on higher cost-sharing tiers, barring the insured from accessing the drug unless he can afford the copayment.<sup>111</sup> This insurance design has proven to cost people several extra thousands of dollars to be able to access their necessary medicines beyond what they may already pay in deductibles and premiums.<sup>112</sup> The ACA caps these out-of-pocket expenditures, but high health care consumers may find themselves reaching that limit each and every year. These types of plans may further entrench the trends in the disabled populations of having higher out-of-pocket cost and being more likely to be unable to pay for needed care.<sup>113</sup> While savvy consumers may be able to find plans that offer them the best cost-

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106. Rosenbaum & Teitelbaum, *supra* note 102.

107. John V. Jacobi et al., *Health Insurer Market Behavior After the Affordable Care Act: Assessing the Need for Monitoring, Targeted Enforcement, and Regulatory Reform*, 120 PENN ST. L. REV. 109, 120–29 (2015).

108. *Id.* at 128.

109. Rosenbaum & Teitelbaum, *supra* note 102.

110. Rosenbaum et al., *supra* note 71, at 534.

111. Douglas B. Jacobs & Benjamin D. Sommers, *Using Drugs to Discriminate—Adverse Selection in the Insurance Marketplace*, 372 NEW ENG. J. MED. 399, 399–402 (2015).

112. *Id.* See also Spenser G. Bengé, *Section 1557 of the Affordable Care Act: An Effective Means of Combatting Health Insurers’ Discrimination Against Individuals with HIV/AIDS?*, 13 IND. HEALTH L. REV. 193, 205–207 (2016) (stating cost for brand name and generic AIDS medication and cost including various insurance plans).

113. LINDER ET AL., *supra* note 52, at 37 (“There are people with disabilities in the pool who are purchasing private insurance through the Marketplace and then when they try to use it they’re discovering—as many other people are too—that the copays are keeping them from receiving health care services.”).

sharing, purchasing the best insurance can be difficult for the disabled for a number of reasons.<sup>114</sup>

Even with improved regulation of the benefits themselves, there is still a matter of adequate coverage of providers. Disabled people may see many, often costly, providers, and it might be impossible to find a plan that covers all necessary providers. Many insurers are moving toward narrow provider networks that do not contract with academic medical centers that provide the only specialty tertiary and quaternary care that disabled people need.<sup>115</sup> Or the model state plans may seek to avoid paying for certain services or providers by only making them available out-of-network and imposing high cost-sharing.<sup>116</sup>

And “[e]ven if plans are equitable on paper, discrimination may occur in their administration.”<sup>117</sup> For example, an investigation into a New York behavioral health subcontractor by the state attorney general showed that the insurer denied coverage at the individual patient claims level 64% more frequently in behavioral health than in medical claims, despite legal protections that suggest that behavioral health ought to be covered to the same degree as other types of health care.<sup>118</sup>

These are just some examples of claims of insurance discrimination coming out of the insurance markets post-ACA. Cuts and limits in benefits can be important mechanisms for insurers to control rising health care costs, promote quality of health care, and ensure that only medically necessary care is delivered, but these mechanisms can also simply be driven by profit-seeking. Even with rational economic intentions, such mechanisms may still differentially impact the disabled, harming their ability to access necessary medical care at rates that they can afford. Moreover, discriminatory benefit design (in public or private insurance) may reflect an insurance system that is not

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114. While some plans may offer higher premiums in exchange for better cost-sharing, these plans are not always available. Moreover, it can be difficult for disabled people to know which if any insurance will adequately address their health needs. Coverage documents can be difficult to obtain and understand and sometimes are only available after an individual has already signed up for the plan. The use of navigators to help inform insurance purchases can be particularly important for this group as the purchasing decisions can be complex and the interfaces to purchase can sometimes be inaccessible for certain disabled populations. Yet many insurers are moving toward avoiding or reducing this service, which can be another challenge for the disabled. Linder, *supra* note 52, at 39–40.

115. See Blake, *supra* note 81.

116. LINDER ET AL., *supra* note 52, at 4.

117. Jacobi et al., *supra* note 107, at 175.

118. *Id.* Examples of such denials included denial of residential treatment for a patient with life-threatening anorexia nervosa and requirements that substance abusers must face life-threatening withdrawal to be eligible for inpatient hospital coverage.

fully considering the disabled population when it designs its benefits or is making value judgments about the worth of disabled patients.<sup>119</sup>

While this Article contemplates discrimination by health insurers post adoption of the Affordable Care Act, there is also a possibility at the time of writing this Article, that the ACA will be repealed or will undergo dramatic reformation.<sup>120</sup> Efforts to reduce protections against health-status discrimination or to reduce access to insurance will only make civil rights approaches to addressing health insurance discrimination more important as regulatory frameworks are undermined.

### C. The Role for Civil Rights in Health Insurance

The ACA has done a great deal to advance the interests of the disabled in health care but some benefits discrimination is still possible. History tells us that such discrimination will run rampant if the ACA is repealed. Antidiscrimination law is a critical strategy to combat health insurance discrimination, whether the ACA stands or smolders. Before turning to *Alexander v. Choate* and the access/content distinction, which is the most significant barrier to workable antidiscrimination law in this arena, it is worth briefly contextualizing other barriers to civil rights in health insurance

Disability civil rights laws have frequently been criticized for falling short in their promises to fully integrate the disabled into society generally.<sup>121</sup> This is true even more so in health care, which has not

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119. As Professor Orentlicher notes, rationing decisions may “reflect not only technical medical judgments but also value judgments about the proper balance between medical costs and benefits.” Orentlicher, *supra* note 34, at 60.

120. President Trump has made the ACA repeal and replacement an early goal of his presidency, though it is unclear at this time about when and if Congress will approve a repeal and whether they have a suitable replacement. Maggie Haberman & Robert Pear, *Trump Tells Congress to Repeal and Replace Health Care Law “Very Quickly”*, N.Y. TIMES (Jan. 10, 2017), <https://www.nytimes.com/2017/01/10/us/repeal-affordable-care-act-donald-trump.html>. House Republicans rebuffed the Administration’s first effort at replacing the ACA. See Robert Pear, Thomas Kaplan & Maggie Haberman, *In Major Defeat for Trump, Push to Repeal Health Law Fails*, N.Y. TIMES (Mar. 24, 2017), [https://www.nytimes.com/2017/03/24/us/politics/health-care-affordable-care-act.html?\\_r=0](https://www.nytimes.com/2017/03/24/us/politics/health-care-affordable-care-act.html?_r=0). For an overview of why the ACA was put into place and some of the possible replacement proposals, see generally Timothy Jost, *Taking Stock of Health Reform: Where We’ve Been, Where We’re Going*, HEALTH AFFAIRS BLOG (Dec. 6, 2016), <http://healthaffairs.org/blog/2016/12/06/taking-stock-of-health-reform-where-weve-been-where-were-going/> [<https://perma.unl.edu/49DV-83HA>].

121. See Laurence Paradis, *Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act: Making Programs, Services, and Activities Accessible to All*, 14 STAN. L. & POL’Y REV. 389, 390 (2003) (“Congress itself placed limits on this promise [of inclusion] by including eligibility requirements and undue burden/fundamental alteration exceptions on access requirements. The courts have further eroded the impact of the ADA and section 504 through a series of

enjoyed as much progress in litigation as other areas, like education or employment.<sup>122</sup> In the health care context, this may be in part due to uncertainty in the past about to what extent these laws applied to health insurance. The Rehab Act reached only public insurance like Medicare and Medicaid.<sup>123</sup> The ADA was typically viewed by courts to reach private insurance,<sup>124</sup> but there has been some amount of disagreement as to that, and, in either case, there is an exemption in the law for insurers engaging in underwriting.<sup>125</sup> Even if courts can agree that the ADA applied, then, well-founded financial discrimina-

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interpretations that have narrowed the scope of who is protected by these statutes and limited the substance of what constitutes equal access.”); Samuel R. Bagenstos, *The Supreme Court, the Americans with Disabilities Act, and Rational Discrimination*, 55 ALA. L. REV. 923, 923 (2004) (explaining the Supreme Court “has taken a decidedly restrictive view of the proper scope of federal disability discrimination law.”); Tucker, *supra* note 14, at 338–39 (“[C]ourts are not enforcing the law, but instead are finding incredibly inventive means of interpreting the ADA to achieve the opposite result that the Act was intended to achieve. Judges are only people, generally people without disabilities, who are not yet willing to change the rules of society to require themselves or others to act as good Samaritans.”); see also Roberts, *supra* note 57, at 1976 (arguing that the adoption of the Americans with Disabilities Amendments Act (ADAAA) in 2008 was “an attempt to restore the statute to its original state” after “restrictive court interpretations.”).

122. Orentlicher, *supra* note 34, at 65 (“[T]he courts have developed the principle of reasonable accommodations primarily in non-medical contexts.”); Roberts, *supra* note 57, at 2002 (“[M]uch like the Rehabilitation Act, the ADA has not had a meaningful impact on access to health care for people with disabilities.”).
123. Section 504 of the Rehabilitation Act provides that no qualified individual with a disability shall “solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.” Rehabilitation Act of 1973 § 504, 29 U.S.C. § 794 (2012). Public insurers financed by the federal government fall under this provision.
124. Most courts view insurers as a place of public accommodation regulated by Title III of the ADA. ADA Title III provides that “no individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation” by the owner, lessee, or operator of such a place. 42 U.S.C. § 12182(a) (2012). Some courts held that insurance was not regulated by the ADA because it was not a public accommodation, however. For a detailed discussion of these various courts’ stances, see Timothy Frey, *Your Insurance Does Not Cover That: Disability-Based Discrimination Where It Hurts the Most*, 78 GEO. WASH. L. REV. 636 (2010).
125. Title V of the ADA, provides that “this Act shall not be construed to prohibit or restrict— (1) an insurer. . . health maintenance organization, or any agent, or entity that administers benefit plans, or similar organizations from underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State law . . . .” 42 U.S.C. § 12201(c) (2012). There is some limit on this, in that underwriting should not be a “subterfuge” to allow discrimination. Americans with Disabilities Act, 42 U.S.C. § 12201(c) (2012).



tion was always seen as beyond the reach of the law.<sup>126</sup> Civil rights laws have also been viewed as particularly complex to apply in the context of health care financing.<sup>127</sup>

Beyond the limits of the law, there has been a historical reluctance on the part of disability advocates to focus on health benefits out of fear that such advocacy would be seen as wrongfully favoring a medical over a social view of disability.<sup>128</sup> The medical model of disability saw disability as a medical abnormality in which the disabled body needed to be made to fit the environment around it.<sup>129</sup> This model was critiqued for viewing disabled people as less capable simply because the world was built with recognizing their bodies and needs.<sup>130</sup> It also forced medicalization into disabled who are not “sick”<sup>131</sup> or can-

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126. Wendy E. Parmet, *Discrimination and Disability: The Challenges of the ADA*, 18 L. MED. & HEALTH CARE 331, 340 (1990). As Professor Parmet noted in early writings after the adoption of the ADA, “the ability to . . . shape benefit plans to discriminate against disabilities may well have the effect of undermining many of the Act’s antidiscrimination goals. If benefits packages can be structured to disproportionately harm the disabled, the prejudice and stigmatization that the ADA attempts to outlaw may come in the back door.” For a history of the wide acceptance of actuarially fair discrimination in health insurance, see Crossley, *supra* note 38.

127. Decisions about insurance coverage are “complex, multifactorial decisions. As a result, trying to tease out what role disability plays in the decision-making process and whether that role should be deemed legitimate or illegitimate can be quite problematic.” Crossley, *supra* note 1, at 53. Moreover, civil rights law and health care financing can be contradictory in their goals. “[T]he law of health care financing rests heavily on the law of insurance, which in turn emphasizes the legality of exclusion and risk avoidance. In contrast, civil rights laws enacted to protect persons with disabilities are fundamentally intended to advance the societal embrace of individuals whose health status can carry the potential for a greater consumption of resources.” See Rosenbaum, *supra* note 8, at 426–27.

128. Wendell, *supra* note 24. But see Martha T. McCluskey, *How the Biological/Social Divide Limits Disability and Equality*, 33 WASH. U. J.L. & POL’Y 109, 112 (2010) (rejecting the need to divorce medical from social causes of disadvantage and instead advocating for a system that asks “whose potentially disadvantageous differences are systematically privileged as public concerns deserving public support and whose are penalized as private problems”).

129. Wendell, *supra* note 24.

130. Paula E. Berg, *Ill/Legal: Interrogating the Meaning and Function of the Category of Disability Antidiscrimination Law*, 18 YALE L. & POL’Y REV. 1, 8 (1999) (explaining the medical model of disability “largely consigns individuals with disabilities to a position of passivity and dependence”); see also Michael Ashley Stein, *Disability Human Rights*, 95 CAL. L. REV. 75 (2007) (arguing that the disability human rights paradigm is the more inclusive approach, where society acknowledges value by inherent human worth instead of contribution).

131. Wendell, *supra* note 24 (citing disabled persons’ narratives that persons with cerebral palsy or quadriplegia are not properly identified as sick, and while needing medical treatment like anyone else, are not seeking a medical cure or of being actively ill). Similarly, some groups or individuals who are seen or perceived as having a disability may reject this identity, preferring to view their condition as a culture rather than a disability. One example is some deaf people who view hearing implants as destroying a deaf culture. Tucker, *supra* note 14, at 385.

not be cured.<sup>132</sup> It wrongfully viewed the disabled as charity figures in need of social welfare to cure their disabilities.<sup>133</sup> And when the medical cure failed to fully integrate the disabled, society would sometimes turn to problematic solutions like institutionalization of the disabled.<sup>134</sup>

In contrast, a social model of disability focuses on a social and political system that does not adequately consider or address disabled persons' needs.<sup>135</sup> Disabled people are seen as no less capable than others.<sup>136</sup> Instead, disabilities "are socially constructed phenomena brought about by attitudes toward people with disabilities which, once embedded in social practices and institutions, sustain the disadvantageous social condition of people with disabilities."<sup>137</sup> Under a social model, instead of modifying the disabled body, the world is adjusted to consider a variety of different bodies, for example by altering the build environment to allow disabled people to access public spaces.<sup>138</sup> As Professor Shakespeare observes, impairment is different from disabil-

132. Berg, *supra* note 130, at 7 (explaining the medical model may serve "as unwanted reminders of the vulnerability of the body that all humans inhabit, and of the limited curative capacity of modern medicine."); *see also* Leonard, *supra* note 12, at 3 ("A public policy that views individuals with disabilities as permanently 'sick,' however well intentioned, runs the risk of dispiriting and dehumanizing its would-be beneficiaries.").

133. Tucker, *supra* note 14, at 343–44 ("People with disabilities do not seek handouts or charity from others, nor do they seek to be awarded special favors or entitlements (indeed, the term 'disabled' is used in the ADA rather than the previously used term 'handicapped,' because the term 'handicapped' was viewed as describing one who held his cap in hand, asking for charitable assistance. To the contrary, people with disabilities seek only to be treated in the same manner as people without disabilities are treated. They seek to be placed on equal footing with people without disabilities.").

134. Wendell, *supra* note 24. *See also* Jacobus tenBroek & Floyd W. Matson, *The Disabled and the Law of Welfare*, 54 CAL. L. REV. 809 (1966) (discussing early writings on the need for a movement from institutionalization to integration for the disabled).

135. Professor Michael Oliver is a predominant scholar in the social disability movement beginning with his book, *Social Work with Disabled People* (1983). He credits the UK movement, the Union of the Physically Impaired Against Segregation (UPIAS), with beginning the social disability movement in the 1970s. Mike Oliver, *The Social Model of Disability: Thirty Years On*, 28 DISABILITY & SOC'Y 1024 (2013).

136. *Id.*

137. JEROME E. BICKENBACH, *PHYSICAL DISABILITY AND SOCIAL POLICY* 13 (1993).

138. A third model, the minority group model of disability, builds on the social model and emphasizes that "people with disabilities are a minority group who historically have had, and continue to have, their civil rights violated both by prejudice and by entrenched patterns of exclusionary and segregating behavior on the part of the nondisabled majority." Crossley, *supra* note 12, at 878. This is akin to other forms of discrimination like race and gender. Some who embody this group focus on the technique of "historical counterfactualizing" to ask "how our social landscape would look different if people with disabilities constituted a dominant group in society." *Id.* at 879 (discussing Anita Silvers, *Reconciling Equality to*

ity.<sup>139</sup> Impairment is the private and individual experience while disability is public and structural.<sup>140</sup> This model seeks to accept impairment and remove disability.<sup>141</sup>

This debate somewhat contributes to why health insurance has not been at the forefront of some disability advocates' agendas.<sup>142</sup> Yet, many scholars note that a social model of disability does not require us to reject or ignore the medical needs of the disabled. Even those who advocate for social models of disability recognize health benefits as of central importance to the disabled in order to be healthy enough to engage in society, the primary goal of disability antidiscrimination law. Indeed, some scholars have viewed social participation as the very reason why we as a society ought to provide health care to all of our citizens, disabled or not.<sup>143</sup> In accordance with this idea that health care is good for all, the ACA focuses on health care discrimination being a population problem that affects many groups besides the disabled: the elderly, women, the chronically ill, and others. In emphasizing that discrimination in health insurance is a wider health care finance issue, and not just an issue for the disabled alone, many of the concerns about the charity element of medical models of disability are also removed.

Accepting that civil rights remedies are critical for pursuing equality in health care for the disabled and that discrimination against the disabled by health insurers persists, these cases face their most significant barrier in the form of the harmful precedent of *Alexander v.*

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*Difference: Caring (F)or Justice for People with Disabilities*, HYPATIA, Winter 1995, at 48–52).

139. Tom Shakespeare, *The Social Model of Disability*, in *THE DISABILITY STUDIES READER* 195 (Lennard J. Davis ed., 5th ed. 2017).

140. *Id.*

141. *Id.*

142. Wendell, *supra* note 24, at 18 (observing that in focusing on the medical needs of some disabled, this may foster thinking about the disabled as incapacitated and in need of cure, rather than being in need of social support. It also harkens back to not so long ago efforts to institutionalize the disabled rather than enable them to lead independent lives, which has motivated activists to “distinguish themselves from those who are ill.”).

143. Norman Daniels, *Justice, Health, and Healthcare*, 1 AM. J. BIOETHICS 2, 2 (2001); see also Wendell, *supra* note 24 (“[S]ome unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate . . . . [S]ome very much want to have their bodies cured” in addition to curing ableism as a concept.). Also see Oliver, *supra* note 135, in which the scholar credited with developing the social model clarifies that the social disability movement should not be and was never intended to be entirely exclusive of individual or medical remedies, but rather to broaden what was seen as disability from individual harm to group injury in the form of systematic barriers as a way to increase actions and social movement. See also Shakespeare, *supra* note 139 (noting that one weakness of the social model is that it “so strongly disowns individual and medical approaches, that it risks implying that impairment is not a problem”).

*Choate*.<sup>144</sup> This case has come to stand for a clear and troubling doctrine in disability antidiscrimination law “that an accommodation can be required only if it provides people with disabilities ‘access’ to the same benefit received by nondisabled individuals; an accommodation that would alter the ‘content’ of the benefit will not be required, even if it can be provided at reasonable cost and without undue hardship.”<sup>145</sup>

### III. THE ACCESS/CONTENT DISTINCTION AND HEALTH INSURANCE

Cases that challenge discriminatory benefit design meet a barrier in the form of *Alexander v Choate*, which for thirty years has stood for the notion that discriminatory insurance benefits are outside of the reach of disability antidiscrimination law.<sup>146</sup> This is particularly problematic now that most forms of discrimination post-ACA are in benefit design. The next section will describe *Choate* and its implications for insurance benefits, before turning to strategies to move past its limiting effect in health care.

#### A. *Alexander v. Choate*

*Alexander v. Choate* begins when plaintiffs, a class of disabled Tennessee residents, sued their state Medicaid agency.<sup>147</sup> Faced with an all-too-common Medicaid deficit, the state decided to implement cost-cutting procedures by reducing the number of covered inpatient hospital days from twenty to fourteen.<sup>148</sup> The plaintiffs argued that the cuts violated the Rehab Act by disproportionately harming the disabled who were more likely to need the twenty covered hospital days than their nondisabled counterparts.<sup>149</sup> They argued not only that the specific cut in question was discriminatory because it had a disproportionate effect on the disabled, but also that *any annual limit* on covered days was likely impermissible as having a disproportionate effect on the disabled.<sup>150</sup> The plaintiffs sought injunctive relief to prevent the cuts from moving forward and suggested that the state instead limit inpatient hospital days based on the condition being treated.<sup>151</sup>

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144. *Alexander v. Choate*, 469 U.S. 287 (1985).

145. BAGENSTOS, *supra* note 9, at 71.

146. *See id.*

147. *Alexander*, 469 U.S. at 289.

148. *Id.*

149. According to the uncontested record, over 27% of disabled persons needed more than fourteen hospital days compared with less than 8% of nondisabled. *Id.* at 290.

150. *Id.*

151. For example, if an appendectomy is expected to only require three hospital days, then the state agency could set such a limit. Of course, this cap could also be

A divided panel of the Sixth Circuit agreed that there was a *prima facie* case in support of a violation of the Rehab Act.<sup>152</sup> The state was asked on remand to demonstrate whether there were other ways to achieve similar cost-cutting benefits without disproportionately harming the disabled, or alternatively, to offer substantial justification for the need to make such cuts.<sup>153</sup> Essentially, this court raised the standard of “undue burden” that is frequently seen in Rehab Act and ADA cases—i.e., that a reasonable accommodation is not required if it cannot be reasonably achieved.

In a partial victory, a unanimous Court under Justice Marshall acknowledged that claims alleging disparate impact could move forward under the Rehab Act, and intentional discrimination was not needed.<sup>154</sup> The Court viewed this as necessary to address disability discrimination, which is so often the result of “benign neglect” rather than intentional mistreatment.<sup>155</sup> Architects do not build buildings with an aim toward excluding the disabled, but still they are harmed all the same if they cannot go inside.<sup>156</sup>

Acknowledging that disparate impact must be permitted under the Rehab Act, the Court was then left in a quandary. How could it respect the need for some amount of disparate impact but limit such suits, given that disabled may often be disparately affected by insurance decisions because they are not similarly situated to their nondisabled peers?<sup>157</sup> Health care for the disabled can be costly, and, as the plaintiffs noted, any annual cap on hospital days could be argued to disparately affect the disabled. Could any cuts escape a claim of unlawful discrimination given that cuts must sometimes occur in a state- and federally-funded health care program?

Ultimately, the Court reached for a compromise in the “meaningful access” standard, which was meant to respect the need for some disparate impact claims while keeping “\$504 within manageable bounds.”<sup>158</sup> The Marshall Court rejected the undue burden considerations raised by the Sixth Circuit. Instead, they adopted the “meaningful access” standard which requires entities to ensure “meaningful access” to the programs that their nondisabled counterparts can access, but they need only make a “reasonable” accommodation to suit

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subject to contest, unless it specifically made accommodation for complex cases where more covered days may be medically necessary. *Id.* at 291.

152. *Id.* at 291.

153. *Id.* at 291–92.

154. *Id.* at 292–99.

155. *Id.* at 295.

156. *Id.*

157. *Id.* at 299.

158. *Id.*

the disabled.<sup>159</sup> They need not go so far as to make a fundamental change to the program or a substantial modification.<sup>160</sup>

Applying this standard to the *Choate* plaintiff's argument that the fourteen-day limit was discriminatory, the Court disagreed, holding that plaintiffs had been granted "meaningful access."<sup>161</sup> The cut was neutral, in that it did not take any protected trait into account, for example, by excluding some groups from the benefit while giving it to others.<sup>162</sup> The disabled received the same access to the same benefit as their nondisabled counterparts, no more but no less.<sup>163</sup>

To the argument that the disabled needed more covered inpatient days, the Court essentially saw the question as beyond the bounds of the Rehab Act.<sup>164</sup> The Medicaid agency need not single out the disabled for greater coverage because Medicaid does not guarantee "adequate health care" for its recipients or require plans to be tailored specifically to the needs of particular recipients, even the disabled.<sup>165</sup> The Court, in essence, was unwilling to examine the content of the benefit for whether it was adequate or whether it could be altered, reasonably, to better integrate the disabled. Instead, they saw the benefit as fourteen days, or whatever else the state chose to offer.<sup>166</sup> The question was not what that benefit was or whether it was adequate, or indeed whether it could be changed in an affordable manner to accommodate the disabled, but instead whether the disabled had access to it like others who were not disabled.

The argument that any cut to covered inpatient days would disparately impact the disabled was likewise rejected for similar reasoning.<sup>167</sup> This was seen by the Court as essentially another request for accommodation that need not be granted.<sup>168</sup>

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159. *Id.* at 301.

160. *Id.* This standard was adopted from a prior Rehab Act case, *Southeastern Community College v. Davis*, 442 U.S. 397 (1979). In that case, a deaf nursing student sought accommodation to attend a registered nursing program by asking for a classroom attendant and removal of the obligation to attend clinical classes. The Court rejected her accommodation request as fundamental alteration of the program, in part, because the accommodation was "far more than the 'modification' the regulation require[d]." *Id.* at 410. The *Davis* Court believed that such accommodation would fundamentally alter the nursing program, that Davis couldn't practice as a registered nurse, and that Davis wouldn't benefit from the accommodation. *Id.* at 407–14.

161. *Alexander*, 469 U.S. at 302–06.

162. *Id.* at 302.

163. *Id.*

164. *Id.* at 303.

165. *Id.*

166. *Id.*

167. *Id.* at 306–09.

168. *Id.*

The Court concluded that while the Rehab Act must reach some claims of disparate impact, the cuts under Tennessee Medicaid were not among them.<sup>169</sup> Notably, the Court failed to define what meaningful access was or what types of claims might fall within it.<sup>170</sup>

### B. The Access/Content Distinction Post-*Choate*

Courts since *Choate* have applied the meaningful access standard according to the access/content distinction.<sup>171</sup> If a plaintiff can show that the issue is in the ability to access the benefit itself, she will succeed.<sup>172</sup> However, if the plaintiff already has access to the benefit and the challenge has to do with whether the benefit itself is adequate, for example the disabled person requires more or different benefits, then the claim will fail.<sup>173</sup> The plaintiff is seen as receiving meaningful access if she receives at least the same benefits as everyone else, but no more or no different benefits.<sup>174</sup> That the case alters benefits is used as an affirmative defense which succeeds even if the requested change would be easily and affordably achieved.

While this doctrine extends beyond health insurance,<sup>175</sup> nowhere has *Choate* “drained the statute of effectiveness” so much as in the case of health insurance, where the content can so effectively discrimi-

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169. *Id.* at 309.

170. Leslie Pickering Francis & Anita Silvers, *Debilitating Alexander v. Choate: “Meaningful Access” to Healthcare for People with Disabilities*, 35 FORDHAM URB. L.J. 447, 452–53 (2008).

171. BAGENSTOS, *supra* note 9, at 73.

172. *Id.* at 71.

173. *Id.*

174. One significant exception appears to be *Olmstead v. L.C.*, 527 U.S. 581 (1999) where the Court avoided the access/content distinction by viewing the case as more about administration of benefits than more or different benefits. Plaintiffs were disabled persons in need of long-term care. While their physicians said that institutional care was inappropriate for them, community-based care was not funded enough by the state for there to be openings for them. They sued, alleging discrimination on the basis of disability under the ADA. They won, because the Court distinguished their claim from *Choate*. The Court did not see this as a matter of benefits, i.e., that the plaintiffs wanted more or better access than nondisabled counterparts, because the state had already agreed to provide the benefit (community-based care). Instead, they were able to frame the problem as one of access because the problem was that they were not administering that benefit in a way that protected these disabled persons. This is largely a matter of framing, but again, courts may be reluctant to broadly frame matters as ones of administration instead of benefit design and we certainly have not seen a turning away of the access/content distinction since *Olmstead*. For more on *Olmstead* as compared to *Choate*, see Rosenbaum, *supra* note 8.

175. Bagenstos, *supra* note 1, at 39 (arguing that in *Doe v. Omaha*, “Judge Posner made clear that the access/content distinction was not an insurance-specific doctrine. Rather, it reflected a general limitation on the ADA’s accommodation requirement.”).

nate.<sup>176</sup> A long line of cases have refused to consider discrimination in health insurance benefits because of the access/content distinction in health insurance cases,<sup>177</sup> and health insurance seems to be the most frequent context in which plaintiffs lose because of this distinction.<sup>178</sup>

Though *Choate* was a case dealing with public benefits and the Rehab Act, the access/content distinction has been extended into private insurance and to ADA cases. In *Doe v. Mutual of Omaha*, plaintiffs contested two private insurance plans that placed lifetime limits on benefits for AIDS treatment.<sup>179</sup> The policies limited lifetime benefits for AIDS and related therapy to \$25,000 and \$100,000 respectively.<sup>180</sup> Plaintiffs challenged the private insurance caps under Title III of the ADA, the public accommodation statute.<sup>181</sup>

In a memorable decision by Judge Posner, the AIDS caps were upheld as permissible under the ADA. Similar to *Choate*, the plans offered the same benefits to the disabled as they offered to the nondisabled because all parties were subject to the AIDS cap regard-

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176. Bagenstos, *supra* note 1, at 37.

177. For example, see Bagenstos, *supra* note 1, 41 nn.168–69, for a list of cases where courts refused to consider content-level discrimination either on the basis of the treatment or of the diagnosis. For a case supporting the holding in *Doe* that ADA regulates access to plans but not content, see *Micek v. City of Chicago*, No. 98-C-6757, 1999 WL 966970, at \*6–7 (N.D. Ill. Oct. 4, 1999) (“[P]laintiffs in this case do not assert that the City denies policy access or coverage to disabled persons . . . . Plaintiffs complain [instead that they cannot] receive the treatment and equipment they desire . . . . Accordingly . . . their complaint would fail to state a claim.”).

178. See also Michael Waterstone, *The Untold Story of the Rest of the Americans with Disabilities Act*, 15 VAND. L. REV. 1807, 1845 (2005) (“Similarly, my review of the Title II case law reveals a growing body of Medicaid and health care litigation where courts, applying *Alexander*, decline to change the content of what states offer under Medicaid or other health services programs. This reinforces Bagenstos’s idea that in these types of cases, courts have applied the access/content distinction at a high level of generality.”). In a database he maintained of ADA cases, he found that 82% of Title III cases against insurers had favorable results for the defendant. He points to several cases suggesting that the courts are moving somewhat away from the access/content distinction in Medicaid cases, though, including pointing to *Olmstead* and *Lovell v. Chandler*. Overall, he found the access/content distinction to be most problematic in health insurance, and much less so in other settings:

To be sure, after reviewing the Title III case law, I am convinced that certain categories of cases (primarily insurance cases) basically are no longer useful Title III issue areas, in part because of the concerns that Bagenstos articulates. But there is also a large universe of Title III cases—those involving architectural barriers—that are not as affected by the access/content distinction.

Watersone, *supra*, at 1847.

179. *Doe v. Mut. of Omaha Ins. Co.*, 179 F.3d 557, 558 (7th Cir. 1999).

180. *Id.*

181. *Id.*



less of whether they had AIDS or HIV.<sup>182</sup> To Posner, the plaintiffs sought to change the benefit, not merely to access it:

Mutual of Omaha does not refuse to sell insurance policies to such persons—it was happy to sell health insurance policies to the two plaintiffs. But because of the AIDS caps, the policies have less value to persons with AIDS . . . people with AIDS have medical needs unrelated to AIDS, and the policies give such people as much coverage for those needs as the policies give people who don't have AIDS. If all the medical needs of people with AIDS were AIDS-related and thus excluded by the policies, this might support an inference that Mutual of Omaha was trying to exclude such people, and such exclusion . . . might violate the Act.<sup>183</sup>

By seeking to remove the AIDS cap, plaintiffs went beyond asking for access to altering the content of the benefits:

The common sense of the statute is that the content of the goods or services offered by a place of public accommodation is not regulated. A camera store may not refuse to sell cameras to a disabled person, but it is not required to stock cameras specially designed for such persons.<sup>184</sup>

Accommodation is required to enable access to a benefit, and then only to the extent the accommodation is reasonable.<sup>185</sup> “But no accommodation will be required—no matter how reasonable—if it would alter the content of the opportunity the defendant offers generally.”<sup>186</sup> Notably, the loss of the plaintiffs was entirely because of the access/content distinction, and not any question of whether the ADA applied to the insurers.<sup>187</sup>

### C. Critiques of the Access/Content Distinction

The access/content distinction has been critiqued on a number of grounds related to health insurance. By only looking to whether the disabled have the same benefits as everyone else and not to what the content of those benefits is, the courts truly look past the issue of disparate impact, despite the *Choate* court recognizing disparate impact as permissible.<sup>188</sup> By failing to truly recognize disparate impact, the

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182. *Id.* at 559.

183. *Id.*

184. *Id.* at 560.

185. *Id.*

186. BAGENSTOS, *supra* note 9, at 69.

187. Bagenstos, *supra* note 1, 41 n.170 (highlighting access/content distinction as the primary barrier to change in health insurance and summarizing case law, noting that “[s]ome courts and judges, to be sure, have relied primarily on the safe harbor provision in such cases, but they are a distinct minority”). For a discussion of the safe harbor provisions that insulate insurance underwriting in ADA cases, see *supra* note 125.

188. Crossley, *supra* note 1, at 81 (“[C]ourts fail to recognize the application of disparate impact theory to insurance practices.”); Abbe, *supra* note 11, at 1202 (“Choate’s basic holding, that a blanket cap on health care is not a deprivation of meaningful access, has been repeatedly upheld by courts, but this holding overlooks the fact that treating the disabled and nondisabled exactly alike will not

access/content distinction assimilates accommodation claims as close to traditional antidiscrimination as possible.<sup>189</sup> By forcing plaintiffs to only bring suit where they have been denied outright access, those claims look more akin to facial and intentional forms of discrimination where the remedy is to seek inclusion only.<sup>190</sup> Ultimately, Professor Bagenstos sees this failure to respect accommodation as a consequence of a general forgiveness for rational discrimination.<sup>191</sup> That is, we as society feel we ought to penalize intentional discrimination, but we feel that we ought not to penalize entities where they are simply acting according to their own economic interests and not out of a sense of bias or hatred.<sup>192</sup> This same concept was present in the ADA when it forgave rational economic, actuarially based discrimination with the safe harbor that permits insurers to underwrite.<sup>193</sup> Professor Bagenstos rejects this distinction, however, because even rational discrimination can lead to subordination of groups, which is ultimately what we are seeking to avoid in civil rights law.<sup>194</sup>

Professor Crossley argues that the access/content distinction in health insurance fails to recognize how health insurance is a distinct product from other products.<sup>195</sup> She argues that health insurance and health care are distinguishable from other goods and services because the health insurance market is uniquely discriminatory against the disabled.<sup>196</sup> It segments the market according to risk of consuming health care and thus seeks to avoid the disabled, as opposed to other businesses which would find the disabled as simply another market to sell products to.<sup>197</sup> Likewise, while perhaps a camera store need not sell special cameras, reasonable accommodation seems more necessary in the case of health insurance, which is of both medical and social importance for the disabled and nondisabled alike.<sup>198</sup>

Professor Orentlicher has critiqued the access/content standard for turning the concept of equitable health care allocation upside down.<sup>199</sup>

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result in the same benefits for the two groups; otherwise, there would be no need for a Rehabilitation Act or an ADA.”).

189. BAGENSTOS, *supra* note 9, at 69.

190. *Id.*

191. Samuel R. Bagenstos, “Rational Discrimination,” *Accommodation, and the Politics of (Disability) Civil Rights Law*, 89 VA. L. REV. 825, 848–49 (2003).

192. *Id.* at 851.

193. *See supra* note 125.

194. *Id.* at 851–52.

195. Crossley, *supra* note 1, at 83–84.

196. *Id.*

197. *Id.*

198. As Crossley wryly notes, while the number of people without cameras might match the number of uninsured, “I have heard no politician spinning forth elaborate and expensive proposals to increase camera ownership by Americans.” *Id.* at 84.

199. Orentlicher, *supra* note 34, at 80.

Let alone failing to enable reasonable accommodation, it creates and perpetuates an unfair system.<sup>200</sup> It “permits unequal treatment as long as everyone receives a decent minimum level of the benefit.”<sup>201</sup>

The access/content distinction also contributes to a harmful fragmentation in civil rights, a theory introduced by Professor Satz.<sup>202</sup> According to her theory of fragmentation, civil rights laws only apply to certain people at certain times, irrespective of whether an individual needs protection outside of those narrowly defined legal categories.<sup>203</sup> “[A]n individual may be able to enter a workspace, board a public bus, or enter a shopping mall, but that does not mean that she will be able to work, travel to a desired destination, or shop.”<sup>204</sup> Likewise, the civil rights claim in health insurance can only get a plaintiff so far. It can help them to purchase a plan but not to ensure that the plan actually has any value for them as a disabled person.

Perhaps most significant, the access/content distinction limits dialogue in the courts around several important legal and policy issues. By avoiding reasonable accommodation, the benefit/access distinction stunts a conversation about what it would require to create equal benefits for the disabled. It also completely ignores whether any additional benefits not covered in the four corners of a given plan might be necessary for disabled populations. And it removes the opportunity to explore whether or not an accommodation would even be feasible.<sup>205</sup> As Professor Bagenstos notes, “[t]hese doctrines categorically exclude certain classes of accommodation from the purview of [disability law]—even if the requested accommodations could be provided reasonably and without undue hardship.”<sup>206</sup> It fails to explore to what extent an insurer, even a rational for-profit insurer, might be able to accommodate certain special needs of the disabled, whether in the form of less cost-sharing, greater access, or additional benefits.<sup>207</sup> As Professor Rosenbaum explains it, even if the change is not costly and even if the practice is discriminatory, such changes to benefits are seen as so “administratively burdensome that they exceed what the ADA requires the public entity to reasonably do. In effect, the issue becomes a matter for the political, rather than the judicial, process.”<sup>208</sup>

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200. *Id.*

201. *Id.*

202. Ani B. Satz, *Overcoming Fragmentation in Disability and Health Law*, 60 EMORY L.J. 277, 289 (2010).

203. *Id.*

204. *Id.* at 289.

205. Bagenstos, *supra* note 1.

206. *Id.* at 35.

207. *Id.*

208. Sara Rosenbaum, Joel Teitelbaum, D. Richard Mauery, & Alexandra Stewart, *Reasonable Modification or Fundamental Alteration? Recent Developments in*

Overall, courts continue to view discriminatory benefit design as outside the scope of disability antidiscrimination law because of the access/content distinction. The next section argues that administrative agencies and Congress have moved past the access/content distinction and that the courts should follow and fully engage the question of accommodation in health insurance.

#### IV. REINSTATING CIVIL RIGHTS FOR THE DISABLED IN HEALTH INSURANCE

The access/content distinction coming out of *Choate* has rendered disability-based discriminatory health benefits untouchable by civil rights law for over thirty years. But there is evidence that agencies are willing to look beyond the access/content distinction in their review of insurance plans and in agency complaints. Courts should do the same. This section argues that section 1557 of the ACA allows DHHS/OCR, the agencies tasked with reviewing insurance plans for discrimination, to move beyond the access/content divide and to fully consider benefit discrimination based on newly implemented rules. Second, if agencies are to stray from this access/content distinction, the Article argues that courts also should, and should use agency guidelines as a starting point for a new legal standard to review benefit discrimination.<sup>209</sup>

##### A. Section 1557, Agency, and the Access/Content Distinction

The final rules for section 1557 of the ACA, in effect, move past the access/content distinction requiring DHHS/OCR and the courts to consider claims of benefit discrimination under section 1557. This section describes how DHHS/OCR rejects the access/content distinction and what standard they will apply in its place.

###### 1. Section 1557

Congress enacted section 1557, a new health care-specific civil right, as part of the ACA.<sup>210</sup> Section 1557 uniquely extends four distinct civil rights laws, Title VI, Title IX, the Age Discrimination Act, and the Rehab Act, to health care programs that are receiving federal

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*ADA Caselaw and Implications for Behavioral Health Policy*, CTR. FOR HEALTH SERVICES RES. AND POL'Y (Feb. 2003), [http://hsrsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1005&context=sphhs\\_policy\\_briefs](http://hsrsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1005&context=sphhs_policy_briefs).

209. There are good normative reasons to question *Choate*'s access/content distinction, as well, as nodded to *supra* Part III.

210. Patient Protection and Affordable Care Act, 42 U.S.C. § 18116(a) (2012). See Sidney D. Watson, *Section 1557 of the Affordable Care Act: Civil Rights, Health Reform, Race, and Equity*, 55 HOW. L.J. 855, 859 (2012) (arguing that section 1557 is uniquely applied to health care).

funding.<sup>211</sup> Section 1557 is a broad-sweeping civil rights standard created in response to increased federal expenditures in health care, in health insurance, and other forums.<sup>212</sup> The statute is broad-sweeping and suggests an effort on the part of Congress to widely protect civil rights in health care. Likewise, the final rules published in May 2016<sup>213</sup> by DHHS/OCR also suggest an intent to broadly prohibit discrimination in health care.

Section 1557 applies to public insurance<sup>214</sup> and private insurance under its purview.<sup>215</sup> In the realm of private insurance, federal subsidies and tax credits designed to defray the cost of private insurance are encompassed in the definition of federal financial assistance.<sup>216</sup> Thus an insurer offering a plan on a state or federally facilitated exchange will come under section 1557's reach if any of their enrollees pay their premiums in part with a federal subsidy or tax credit.<sup>217</sup> This addresses virtually all private insurers offering plans on the ex-

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211. Section 1557 applies to "any health program or activity, any part of which is receiving Federal financial assistance . . . , or under any program or activity that is administered by an Executive Agency or any entity established under [Title I of the Act or its amendments]." Patient Protection and Affordable Care Act, 42 U.S.C. § 18116(a) (2012). Uniquely, section 1557 addresses discrimination in health care against several different protected classes, whose protections stems from different civil rights laws and doctrine.

212. As President Kennedy noted in forming civil rights laws like Title VI, "Simple justice requires that public funds, to which all taxpayers of all races [colors, and national origins] contribute, not be spent in any fashion which encourages, entrenches, subsidizes or results in racial [color or national origin] discrimination." *Title VI of the Civil Rights Act of 1964* 42 U.S.C. § 2000D ET SEQ, U.S. DEP'T OF JUSTICE, <https://www.justice.gov/crt/fcs/TitleVI-Overview> [<https://perma.unl.edu/DCG5-5A7K>].

213. Nondiscrimination in Health Programs and Activities, 45 C.F.R. § 92 (2016).

214. 45 C.F.R. § 92.4 (2016) (explaining a "health program or activity also includes all of the operations of a State Medicaid program, a Children's Health Insurance Program, and the Basic Health Program," but note that the definition of Federal financial assistance does not include Medicare Part B).

215. *Id.* ("Federal financial assistance the Department provides or otherwise makes available includes Federal financial assistance that the Department plays a role in providing or administering, including all tax credits under Title I of the ACA, as well as payments, subsidies, or other funds extended by the Department to any entity providing health-related insurance coverage for payment to or on behalf of an individual obtaining health-related insurance coverage from that entity or extended by the Department directly to such individual for payment to any entity providing health-related insurance coverage.").

216. Nondiscrimination in Health Programs and Activities, Regulatory Impact Analysis, 81 Fed. Reg. 31,375, 31,445 (May 18, 2016) ("Qualified health plan issuers receiving Federal financial assistance through advance payments of premium tax credits and cost-sharing reductions (which include at least the 169 health insurance issuers in the Federally-facilitated Marketplaces receiving Federal financial assistance through advance payments of premium tax credits and cost sharing reductions and at least 11 issuers operating in the State-Based Marketplaces that we were able to identify)").

217. *Id.*

change. Those insurers' nonexchange plans are also regulated, along with any insurance plan that they function as a third party administrator for.<sup>218</sup> This last part captures many large group plans, as insurers will often offer small and individual insurance, as well as acting as third party administrator for large group plans.<sup>219</sup>

Additionally, section 1557 extends to Medicare and Medicaid and to DHHS in its administration of health care programs.<sup>220</sup> The law also covers individual, small group, and large group insurers or administrators who receive other federal funds, for example through federal grants.<sup>221</sup> As evidence of DHHS/OCR's efforts to make section 1557 have teeth, the regulations broaden private rights of action in disparate impact to all four civil rights statutes under section 1557, even though these same actions are not available for some of these statutes outside of health care.<sup>222</sup>

218. See Nondiscrimination in Health Programs and Activities, Summary of Regulatory Changes, 81 Fed. Reg. 31,357, 31,429 (May 18, 2016). ("We provided an example illustrating that an issuer participating in the Marketplace<sup>SM</sup>, and thereby receiving Federal financial assistance, that also offers plans outside the Marketplace<sup>SM</sup> would be covered by the regulation for all of its health plans, as well as when it acts as a third party administrator for an employer-sponsored group health plan.")

219. For example, if a Blue Cross state plan offers itself on the exchange, then section 1557 will apply to all of its insurance products: small group and individual insurance products it sells on and off the exchange and its function as third-party administrator of employer sponsored plans. There does appear to be a significant loophole created here by the final rules of section 1557. DHHS/OCR acknowledges that when it comes to benefit design, it will frequently be an employer who designs benefits rather than a third-party administrator. Section 1557 does not extend to employers unless they are a health care activity in their own right that receives federal funds. When an employment insurance plan is viewed as being discriminatory, DHHS/OCR will look to who created the plan. If it was created by the insurance entity as a third party, they can be accountable under section 1557. If it's the employer, then it can only be accountable if it is a covered health care entity (like an insurer themselves, or some hospitals, or health care organizations). 45 C.F.R. § 92.207 (2016).

220. See *supra* note 243.

221. "Federal financial assistance" includes grants, loans, and other types of assistance. See 45 C.F.R. § 92.4 (2016).

222. The final rule for section 1557 was published on May 18, 2016, and it seeks to create a unified standard for section 1557 and for all of its relevant protected classes, for example, by permitting private causes of action for disparate impact claims in all of the four protected classes. This includes Title VI cases in which private causes of action are not permitted outside of section 1557 such as in *Alexander v. Sandoval*, 532 U.S. 275 (2001). See Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. 31,375, 31,439 (May 18, 2016) (quoting *Rumble v. Fairview Health Servs.*, No. 14-CV-2037, 2015 WL 1197415, at \*11 (D. Minn. Mar. 16, 2015)) ("It appears that Congress intended to create a new, health-specific, anti-discrimination cause of action that is subject to a singular standard, regardless of a plaintiff's protected class status. Reading Section 1557 otherwise would lead to an illogical result, as different enforcement mechanisms and standards would apply to a Section 1557 plaintiff depending on whether the

Section 92.207 of section 1557's regulations addresses discrimination in health insurance.<sup>223</sup> Section 92.207 requires that "[a] covered entity shall not, in providing or administering health-related insurance or other health-related coverage, discriminate on the basis of race, color, national origin, sex, age, or disability."<sup>224</sup> In terms of access to health insurance, insurers are prohibited from discriminating on the basis of protected class in denying, cancelling, limiting, or refusing to issue/renew a health insurance plan.<sup>225</sup> Marketing practices designed to discriminate are also prohibited.<sup>226</sup>

Section 92.207 also addresses content-side discrimination by insurers.<sup>227</sup> It explicitly forbids discriminatory "benefit designs" on the basis of disability, as well as age, race, and gender.<sup>228</sup> Insurers may not deny or limit claims or impose different cost-sharing (e.g., deductibles, coinsurance, copays) on the basis of any of these protected classes.<sup>229</sup>

## 2. *Section 1557's Impact on the Access/Content Distinction*

DHHS/OCR, as an agency, effectively overturns *Choate* in function, if not in name, in the section 1557 final rule. DHHS/OCR makes no mention of the "meaningful access" standard with respect to insurance, though it does recognize (as required by the ADA) that entities need not fundamentally alter their programs to accommodate.<sup>230</sup> The agency, though, explicitly rejects the access/content distinction by specifying that benefit design can be discriminatory for all four of protected classes, including disability.

If benefit design can be viewed as discriminatory and there are implementing regulations to suss out such discrimination, then it can no longer be, at least according to DHHS/OCR, that benefit-level discrimination is off the table for ADA/Rehab suits. Whatever amounts to fundamental alteration now, the agency recognizes that benefit design

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plaintiff's claim is based on her race, sex, age, or disability. For example, it would not make sense for a Section 1557 plaintiff claiming race discrimination to be barred from bringing a claim using a disparate impact theory but then allow a Section 1557 plaintiff alleging disability discrimination to do so.")?

223. 45 C.F.R. § 92.207 (2016).

224. *Id.*

225. *Id.*

226. *Id.*

227. *Id.*

228. *Id.*

229. *Id.*

230. It adopts this standard in that it requires modifications to only be reasonable and not rise to the level of a fundamental alteration to a program. 45 C.F.R. § 92.205 (2016) ("A covered entity shall make reasonable modifications to policies, practices, or procedures when such modifications are necessary to avoid discrimination on the basis of disability, unless the covered entity can demonstrate that making the modifications would fundamentally alter the nature of the health program or activity.").

can be considered and addressed through section 1557.<sup>231</sup> Moreover, DHHS/OCR refused to explicitly address whether or not “a modification to add medically necessary care, or a prohibition on exclusions of medically necessary services, is never a fundamental alteration to a health plan” thus leaving the door open for suits that claim benefit discrimination.

Either way, in recognizing that “[a] covered entity shall not, in providing or administering health-related insurance. . .[h]ave. . .benefit designs that discriminate on the basis of. . .disability,”<sup>232</sup> DHHS/OCR has effectively rejected the access/content distinction as applied to disability antidiscrimination cases. The access/content distinction is rendered moot because DHHS/OCR acknowledges that benefit design is part of the type of discrimination against disability that will be considered in section 1557. Though DHHS/OCR did not explicitly acknowledge its rejection of this standard, there can be no other conclusion, as how else could one consider discrimination in benefit design if not by reaching to and addressing the content of the insurance?

The recognition that benefit design can be discriminatory is momentous, and it should do much to further the interests of the disabled in health care. Even more though, DHHS/OCR in recognizing that benefit design can be discriminatory under section 1557, also advances some guidance on how to assess what is or is not discriminatory. DHHS/OCR makes clear that insurers still have freedom to define what is medically necessary<sup>233</sup> and to leave off certain benefits and services.<sup>234</sup> Beyond this, in assessing benefit limits or denials of service, the agency will look to four factors: (1) whether coverage for the same or a similar service or treatment is available to individuals outside of that protected class; (2) whether it is available to those with different health conditions; (3) the reasons for any differences in coverage; and (4) whether there is a neutral, nondiscriminatory reason for the denial or limitation that is not a pretext for discrimination.<sup>235</sup> For example, they posit that if bariatric surgery were covered for adult patients but not for adults with developmental delays, it would be considered discriminatory on the basis of disability.<sup>236</sup> This example looks like it does not reach beyond the access/content distinction—the disabled party is only asking for access to the same benefit that others

231. Nondiscrimination in Health Programs and Activities, General Comments, 81 Fed. Reg. 31,375, 31,377 (May 18, 2016).

232. 45 C.F.R. § 92.207 (2016).

233. *Id.* (stating that section 1557 is not “intended to determine, or restrict a covered entity from determining, whether a particular health service is medically necessary or otherwise meets applicable coverage requirements in any individual case.”).

234. *Id.*

235. *Id.*

236. *Id.*



receive, not for an alteration of the benefits. However, DHHS/OCR has indicated that it will look beyond the question of just whether other groups have access to the benefit to the other three factors. These changes by the agency to consider benefits discrimination through these four factors should apply to states and federal government as they review insurers for listing on the exchanges, to the insurers themselves to ensure they are in compliance, and to DHHS/OCR in reviewing complaints.

Given this momentous movement to recognize benefits discrimination, DHHS/OCR should consider introducing additional regulations that delve into the context of discriminatory benefit design and provide examples for where a neutral, nondiscriminatory benefit design exists and examples where an exclusion or a benefit limit is non-neutral and discriminatory,<sup>237</sup> particularly given that state regulators who evaluate these insurance plans for compliance with the ACA admit to not being certain, to date, on what constitutes a discriminatory benefit.<sup>238</sup> In such a regulation, DHHS/OCR should also make a clear and unequivocal statement that it rejects the access/benefit distinction.

DHHS/OCR's guidance on benefits for transgender patients provides an example of how the agency could consider benefit design discrimination under the current rules.<sup>239</sup> The rule requires that some level of services be covered for gender reassignment, regardless of the fact that this creates a benefit additional to and beyond that of people not undergoing gender reassignment.<sup>240</sup> The rule also forbids "categorical coverage exclusion[s] or limitation[s] for all health services related to gender transition," and insurers must cover at least some gender transition services, even if they are relatively affordable therapies like hormone treatment, rather than expensive therapies like

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237. The Family Equality Council has also called for clear standards to address "benefit designs that are facially neutral but that have the effect of systematically disadvantaging members of protected class;" they propose a number of regulatory efforts to help identify discrimination in benefit design including trained evaluators to regularly review insurance contracts for protected class discrimination. Comment Letter of the Family Equality Counsel on Proposed Rule on Patient Protection and Affordable Care Act; Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation (Dec. 20, 2012), [http://www.familyequality.org/\\_asset/cst5jd/Family-Equality-Council-Comments-for-HHS-EHB-Proposed-Rule-12\\_20.pdf](http://www.familyequality.org/_asset/cst5jd/Family-Equality-Council-Comments-for-HHS-EHB-Proposed-Rule-12_20.pdf) [<https://perma.unl.edu/CU46-QQBH>]. See also Keith, *supra* note 107 (suggesting how data mandated to be collected by the ACA can be used to support a study of discriminatory benefit design; for example, section 4302 of the ACA mandates the gathering of information on health disparities of the disabled).

238. Keith, *supra* note 107. The researchers undertook an interview-based study of insurance regulators in several states who described uncertainty in what constitutes discriminatory benefit design.

239. 45 C.F.R. § 92.207 (2016).

240. *Id.*

gender reassignment surgeries.<sup>241</sup> The agency rationalizes their decision because such therapies were, in the past, frequently excluded from insurance as experimental, and this is no longer supported by current standards of care.<sup>242</sup> While DHHS could have achieved the same outcome by mandating gender reassignment as an aspect of EHB, DHHS/OCR specifically chose to define this as a civil rights issue.<sup>243</sup> Particular services that have long been denied to the disabled may be paralleled to the context of gender reassignment surgery. Here, the agency did not just look to whether the denial involved access to benefits or content; instead they looked to the reason behind the long-standing failure to cover that benefit and found it discriminatory in its purpose. Under this same logic, the agency might consider longstanding failure to cover certain durable equipment or habilitative services (or to truly achieve parity with mental health services) as equally wrongful and based on discriminatory reasons rather than any neutral or nondiscriminatory reason.

DHHS/OCR's embrace of design benefit as a form of discrimination is an issue that the agency must hold to in its civil rights hearings. But courts, too, can consider this as a good reason to steer away from access/content distinctions in their section 1557 cases, given the agency's intent to recognize health benefit discrimination as within the purview of section 1557.<sup>244</sup>

## B. The Lost Precedential Value of *Choate*

While DHHS/OCR can be expected to handle complaints about discrimination in benefits differently in reviewing of insurance for offering on the exchange and in agency complaints, courts also have good reason to move away from access/content distinctions. Beyond being convinced by the efforts of the agency that implements these regulations, there is still good reason for them to question the value of *Choate* as precedence post-ACA. As much of this Article has suggested, benefits discrimination and much of health insurance has

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241. *Id.*

242. *Id.*

243. Section 1557 failed to specifically extend civil rights protections to discrimination on the basis of sexual orientation, which is regrettable given the likely possibilities of discrimination in that situation. *See id.* For examples of possible discrimination against such groups in reproductive care, see *N. Coast Women's Care Med. Grp. v. San Diego Cty.* Superior Court, 44 Cal. 4th 1145 (2008) (holding state rights protected a lesbian couple from discrimination by an in-vitro fertilization clinic who denied care on the basis of religious freedom).

244. Conceivably, litigants could challenge aspects of the DHHS/OCR as agency overreach and thus not a standard courts need to defer to out of concern for separation of powers concerns. The author is not aware of any arguments that section 1557 overreaches and is not considering the question of judicial deference to the agency in this Article.

changed since that thirty-year-old opinion. If nothing else, courts should at least reevaluate *Choate* in the context of today's modern health care financing. *Choate* advances several policy arguments to prop up its holding that have lost weight in the context of modern health care financing.

### 1. *Insurer Discretion*

One theme advanced by the *Choate* court is that an accommodation would go against the substantial discretion given to insurers (or the states) in determining the "proper mix of amount, scope, and duration limitations" of their Medicaid benefits.<sup>245</sup> According to the Court, Medicaid was under no obligation to provide adequate health care, instead it was free to define its benefits and then it must only ensure equal access to them:

Medicaid programs do not guarantee that each recipient will receive that level of health care precisely tailored to his or her particular needs. Instead, the benefit provided through Medicaid is a particular package of health care services, such as 14 days of inpatient coverage. That package of services has the general aim of assuring that individuals will receive necessary medical care, but the benefit provided remains the individual services offered-not 'adequate health care.'<sup>246</sup>

Professor Bagenstos has observed that the outcome of applying the access/content distinction depends heavily on how broadly one defines the benefit in question.<sup>247</sup> Because *Choate* defined the benefit as the fourteen covered days, it only needed to ensure equal access by the disabled to those fourteen days.<sup>248</sup> If the Court had, instead, defined the benefit broadly as to include adequate health care, then *Choate*'s plaintiffs could have prevailed because now they are being denied access to the benefit since fourteen days does not amount to adequate health care for them as a class.<sup>249</sup> Courts typically did not view benefits so generously, though.<sup>250</sup>

Similarly, professors Francis and Silvers have argued that the "meaningful access" standard should be read as an equal opportunity standard that requires benefits that have "equal serviceability for disabled and nondisabled alike."<sup>251</sup> For example, a number of non-English speaking plaintiffs have successfully been able to argue denial of meaningful access because, while admitted to educational programs,

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245. *Alexander v. Choate*, 469 U.S. 287, 304 (1985).

246. *Id.* at 303.

247. Bagenstos, *supra* note 1, at 45.

248. *Id.* at 46-47.

249. *Id.* at 47-48.

250. *See id.* *See also* Rosenbaum, *supra* note 8 (noting that civil rights cases challenging health care financing are highly dependent on the facts and it is not always clear which way a court will turn).

251. Francis & Silvers, *supra* note 178, at 477.

they were not able to meaningfully engage in programs without some sort of covered interpretation services.<sup>252</sup> The courts saw mere access as not enough—instead, there must be equal opportunity to engage with the benefit (here, understanding the lectures) in order to have meaningful access.<sup>253</sup> Neither of these views have gained major traction in the courts yet, so courts frequently allow defendants a wooden application of access/content as an affirmative defense.

However, Medicaid itself has mandatory benefits, or benefits that all states must cover in order to obtain federal match dollars to help fund their programs.<sup>254</sup> These mandated benefits are part of what makes Medicaid so pragmatically useful for the disabled, because it requires comprehensive coverage of certain types of services. In crafting the essential health benefits for private insurance, Congress also recognized that there is a minimum, universal level of benefits that all insurers must cover, at least in the private market and other markets where EHBs apply (including some Medicaid plans).<sup>255</sup> Other measures in the ACA target adequacy of benefits in these insurance markets. The law caps out-of-pocket spending for essential health care<sup>256</sup> and requires no cost-sharing for basic preventive services.<sup>257</sup> The law also regulates plans for their actuarial value, requiring plans to cover a minimum percentage of the cost of services.<sup>258</sup> All of these rules reflect a certain value: that there is at least some minimum value that health insurance must meet or it is no longer functioning as adequate health care coverage for the disabled or for any other person. This reflects a significant departure from the understanding of in *Choate* that insurers had free rein to define their benefit packages and that their broad goal was not adequate health.<sup>259</sup>

One can view this according to Professor Bagenstos's argument about defining the benefit.<sup>260</sup> With both EHB and mandatory benefits

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252. *Id.* at 456–57.

253. *Id.*

254. See *List of Medicaid and CHIP Benefits*, MEDICAID.GOV, <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/Downloads/List-of-Medicaid-and-CHIP-Benefits.pdf> [<https://perma.unl.edu/C7C3-WQJD>].

255. Patient Protection and Affordable Care Act § 1302, 42 U.S.C. § 18022(2012) (extending EHB provisions to private insurers and to Medicaid expansion plans.) Indeed, some insurance plans had to be taken off the market because they did not offer robust enough coverage. This was at the center of the much publicized controversy when President Obama said you can keep your health plan if you like it. Plans then had to be removed because they did not offer essential health benefits, or did not do so at an appropriate actuarial value (shifting too much of the cost onto the consumer).

256. *Id.* § 1302(c), 42 U.S.C. § 18022(c).

257. *Id.* § 2713, 42 U.S.C. § 300gg-13.

258. *Id.* § 1302(d), 42 U.S.C. § 18022(d).

259. *Alexander v. Choate*, 469 U.S. 287, 303 (1985).

260. Bagenstos, *supra* note 1, at 28.

under Medicaid, we have a broader benefit: essential health benefits. Access is not enough unless it reflects some level of essential or adequate care for people. Alternatively, we can view it as a shift in what counts as meaningful access akin to the arguments advanced by Francis and Silvers.<sup>261</sup> It is not enough in these programs to have access to any old plan; it must offer meaningful benefits, akin to education cases which critique the benefit for whether it actually allows the user to meaningfully engage with it.<sup>262</sup>

Some might argue that essential health benefits and mandatory benefits are not the same as adequate health care for the disabled. However, the movement to regulate benefits for adequacy across both public and private insurers is enough to question the access/content distinction, which was overly ambivalent to quality of benefits. Moreover, EHBs are supposed to not be designed to take into account only average health care needs.<sup>263</sup> As DHHS notes in its final rules, the Secretary must not discriminate on the basis of disability and must consider the particular health needs of the disabled in establishing the EHBs.<sup>264</sup> So adequate benefits now mean equal access to an essential benefit package that is nondiscriminatory and broadly considers the health needs of the disabled.

Moreover, by recognizing that insurance design can be discriminatory according to a civil rights framework, DHHS/OCR has removed some discretion from insurers.<sup>265</sup> DHHS/OCR, not the insurers, now can create some standard for what amounts to permissible discretion in benefits, and what goes beyond that is unlawful discrimination.<sup>266</sup> Thus benefit determinations are no longer unregulated; they are regulated both by DHHS/OCR and by EHBs.<sup>267</sup> Thus, deference to insurers' discretion to define their own benefits no longer seems appropriate. Likewise, the same is true in Medicaid, where Congress has set forth mandatory benefits. Insurers/states may have discretion in their benefit design but only to a point where it is not discriminatory or in conflict with law.

## 2. *Administrative Burden*

The *Choate* Court was worried, as a practical matter, that it would be administratively burdensome to ask an insurer to evaluate their benefits for whether they discriminate.<sup>268</sup> According to the Court, be-

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261. Francis & Silvers, *supra* note 178.

262. *Id.*

263. See *supra* notes 78–81 and accompanying text.

264. See *supra* notes 78–81 and accompanying text.

265. 45 C.F.R. § 92.207 (2016).

266. *Id.*

267. See *supra* section III.A; 45 C.F.R. § 92.207 (2016).

268. *Alexander*, 469 U.S. at 298.

cause the disabled are frequently not similarly situated to the nondisabled:

[R]espondents' position would in essence require each recipient of federal funds first to evaluate the effect on the handicapped of every proposed action that might touch the interests of the handicapped, and then to consider alternatives for achieving the same objectives with less severe disadvantage to the handicapped. The formalization and policing of this process could lead to a wholly unwieldy administrative and adjudicative burden.<sup>269</sup>

This is a legitimate concern for private and public insurers alike, particularly as administrative burden can contribute to rising health care costs.<sup>270</sup> However, the task of evaluating plans for disability-based discrimination is no longer optional. All plans being offered on the exchange are reviewed by a state agency or federal agency for compliance with ACA rules before being certified and placed on the exchange.<sup>271</sup> Plans are reviewed for whether they offer an adequate array of providers,<sup>272</sup> for whether the plan covers the essential benefits set forth by the state's benchmark plan,<sup>273</sup> for whether the plan is discriminatory,<sup>274</sup> for whether it offers benefits to a certain level of cost-sharing,<sup>275</sup> and for whether the plan engages in any sort of deceptive marketing practices,<sup>276</sup> among other things. Complaint processes exist for consumers to challenge plans.<sup>277</sup> Plans can be retroactively decertified and can be expected to fall into regulatory compliance before being recertified.<sup>278</sup> Thus, an administrative system for reviewing plans is now in place, and one that is far more exhaustive than what the *Choate* Court might ever have contemplated.

More to the point, plans are supposed to be examined for compliance with EHB provisions and civil rights law which require that they not discriminate against the disabled.<sup>279</sup> Public insurers are increasingly regulated, as well, and are sometimes accountable under the

269. *Id.*

270. Aliya Jiwani et al., *Billing and Insurance-Related Administrative Costs in United States' Health Care: Synthesis of Micro-Costing Evidence*, 14 BMC HEALTH SERVICES RES. 556 (2014).

271. "An Exchange shall, at a minimum— (A) implement procedures for the certification, recertification, and decertification, consistent with guidelines developed by the Secretary under subsection (c), of health plans as qualified health plans." Patient Protection and Affordable Care Act, 42 U.S.C. § 18031(d)(4)(A) (2012).

272. *Id.* § 18031(c)(1).

273. *Id.* § 18031(d)(4)(A).

274. Plans should "meet marketing requirements, and not employ marketing practices or benefit designs that have the effect of discouraging the enrollment in such plan by individuals with significant health needs." *Id.* § 18031(c)(1)(A).

275. *Id.* § 18031(d)(4)(A).

276. *Id.* § 18031(c)(1)(A).

277. States can receive grants from the federal government to have navigator who handle and report patient grievances related to insurance denials.

278. 42 U.S.C. § 18031(d)(4)(A).

279. *See supra* section III.A; 45 C.F.R. § 92.207 (2016).

ACA as well as other regulations. A call for insurers to evaluate their plans for disability discrimination is no longer burdensome. Instead it is legally required, if they want to avoid civil rights complaints or possible decertification from the exchange.

### 3. *Adequate Health Benefits*

While the *Choate* Court emphasized that plans were not required to offer adequate health benefits, they were also concerned that such a standard would be impossible to define.<sup>280</sup> The Court was right to be nervous at defining adequate health and to recognize it as an amorphous and challenging concept. However, the perfect can be the enemy of the good. The ACA has in fact attempted to define some standard of adequate health, or at least adequate health *benefits*, with the adoption of the EHB.<sup>281</sup> The Secretary and the states work collaboratively to ensure that insurers cannot completely race to the bottom with the meagerness of benefits they offer. This is an ongoing process to recognize what ought to be covered under EHB, how to guarantee that EHBs are consistent and fair across all states, and how to make sure that they reflect general commonplace health care needs but also still take into account the needs of certain populations like the disabled or children.<sup>282</sup> Likewise, we have Medicaid's mandatory and optional benefits as examples.

While defining adequate health may be challenging, it is no longer true that a court, in evaluating discrimination in a case like *Choate*, would have no standards to look to. Instead, they could look to the EHB provisions. For example, if EHB defines covered inpatient hospital days as an essential benefit, then there is some opportunity for the courts to examine whether that essential benefit has been equally met for the disabled as it has been for other parties.

### 4. *Goals of the Rehab Act*

The last argument invoked by the Court was whether a health insurance case was the right type of case to push the outer limits of disparate impact under the Rehab Act.<sup>283</sup> The Court argued that the Rehab Act set forth a variety of substantive areas where it viewed equality for the disabled to be particularly important, including "employment, education, and the elimination of physical barriers to access."<sup>284</sup> Nothing in the Rehab Act specifically emphasized equality in

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280. *Alexander v. Choate*, 469 U.S. 287, 303–04 (1985) (holding the "Act does not, however, guarantee the handicapped equal results from the provision of state Medicaid, even assuming some measure of equality of health could be constructed").

281. *See supra* section III.A.

282. *Id.*

283. *Alexander*, 469 U.S. at 306–07.

284. *Id.*

health benefits, and thus the Court was reluctant to extend disparate impact too plainly there.<sup>285</sup>

Since *Choate*, there has been an increasing focus on discrimination against the disabled in health care. The ADA was constructed partly with the purpose of combating “discrimination against individuals with disabilities [in] . . . health services.”<sup>286</sup> And while the Rehab Act itself may not have placed health care among its priorities for equality for the disabled, section 1557 has as a health-care-specific civil rights law that specifically protects the disabled from health benefits discrimination.<sup>287</sup> Section 1557 claims are not Rehab Act claims, nor are they ADA claims.<sup>288</sup> Courts should view this distinction with some deference. Just as courts deferred to the failure of Congress to recognize equality in health care as an important goal back then, they should equally pay deference to Congress for creating section 1557 and the ACA and declaring equality in health care as a priority now.

#### V. RESTORING CIVIL RIGHTS TO THE DISABLED IN HEALTH INSURANCE

Expansive civil rights will not solve all of the problems that the disabled face when accessing health care. Many scholars have offered critiques of disability civil rights law generally in creating necessary change for the disabled.<sup>289</sup> Professor Roberts has convincingly argued that civil rights has limits as a paradigm in supporting access to health care for the disabled and that disability advocates can harness both civil rights and health legislation to move forward with improving health care access for the disabled.<sup>290</sup> This Article, too, recognizes ongoing need for improved health care legislation. For example, a

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285. *Id.*

286. 42 U.S.C. § 12101 (2012); *see also* Crossley, *supra* note 1 (summarizing a long list of congressional testimony in support of the adoption of the ADA that detailed extensive barriers that disabled people face in obtaining health care).

287. Sidney D. Watson, *Section 1557 of the Affordable Care Act: Civil Rights, Health Reform, Race, and Equity*, 55 *How. L.J.* 855, 859 (2012) (“Congress intended to create a new health-specific, antidiscrimination cause of action that is subject to a singular standard, regardless of a plaintiff’s protected class.”).

288. *Id.*

289. Bagenstos, *supra* note 1 (arguing that civil rights laws have not addressed a host of systemic barriers for the disabled, particularly in employment, and that disability activists are turning back to a welfare model to supplement their efforts to redress systemic barriers to integration). *See also* Mark C. Weber, *Disability and the Law of Welfare: A Post-Integrationist Examination*, 2000 *U. ILL. L. REV.* 889, 891 (advocating for more expansive and altered welfare programs to “advance beyond the plateau that now has been reached” in disability rights.”). *See also* Satz, *supra* note 202 (arguing that disability law is overly fragmented, treating disabled people as only in need of protection in discretely defined legal limits).

290. Roberts, *supra* note 60. *See also* Pendo, *Shifting the Conversation*, *supra* note 32 (arguing that the ACA and civil rights laws can be complementary in achieving change for the disabled in health care).



more comprehensive essential health benefits provision that did not permit significant state-level reduction in benefits could achieve some of the same effects as civil rights suits and without the expense of litigation.<sup>291</sup> Ongoing market reforms and more stringent monitoring of plans' discrimination could also be regulatory fixes for many of the problems presented in this paper.<sup>292</sup> And universal health benefits would be a significant step towards removing the need for significant civil rights litigation for the disabled.<sup>293</sup>

Yet, in the midst of much reform in health care, and the possibility of greater regulation in the future, there is still a space and a need for civil rights. Access to health insurance means little without access to adequate benefits, and our civil rights need to catch up to this recognition. If nothing else, it seems counter to all that the ACA stands for to have civil rights doctrine that specifically exempts from regulation any health insurers' benefits discrimination against the disabled.<sup>294</sup>

A lingering concern remains from *Choate*, though. Should we and can we limit the scope of disparate impact in health insurance, given that the disabled frequently are not on equal footing with their nondisabled counterparts in their need for health care and claims for accommodation could be boundless and costly?<sup>295</sup> Some may argue that insurers should be exempt from disability discrimination law, or that it must be limited, mainly on the basis that permitting such suits would destabilize the insurance market.<sup>296</sup>

One should look to the ACA and section 1557, though, to combat such arguments. First, many of the ACA's more noteworthy provisions are designed to tackle health status discrimination and to attempt to equalize financial burden in the face of the very real truth that *Choate* underscored—that some people may need more health care than others.<sup>297</sup> The ACA has been designed to stabilize the insurance market to adjust for a variety of reforms that create a more inclusive insurance market, not just civil rights cases.<sup>298</sup> Even more though, the ACA sets a new tone, distinct from the era of *Choate*, that underscores the importance of people with significant health needs be-

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291. Rosenbaum & Teitelbaum, *supra* note 102.

292. Roberts, *supra* note 60.

293. Roberts, *supra* note 1 (advocating universal health benefits as a solution to ongoing instances of discrimination in the insurance market post-health care reform).

294. See 45 C.F.R. § 92.207 (2016).

295. *Alexander v. Choate*, 469 U.S. 287, 298 (1985).

296. Crossley, *supra* note 12 (offering general arguments as to when and why reasonable accommodation may be limited in health care).

297. See *Alexander*, 469 U.S. at 287.

298. Mark A. Hall, *The Three Types of Reinsurance Created by Federal Health Reform*, 29 HEALTH AFF. 1168 (2010) (providing general background on how the ACA was designed to stabilize the insurance industry in the face of limiting insurers' risk avoidance).

ing able to access health insurance. It shifts the cost of illness from sick individuals onto society, embracing a more collective approach to health care financing.<sup>299</sup> This should make us rightly question the use of civil rights as a shield to protect insurers' disability discrimination.

To truly realize the goals of civil rights laws for the disabled, the courts and DHHS/OCR must be willing to consider reasonable accommodation in health benefits, as they would in other settings. Reasonable accommodation in health insurance, like any other situation, would first require that the courts review benefits claims for discrimination and not outright dismiss them according to the access/content distinction. In reviewing this question, both courts and agencies may look to the factors advanced by DHHS/OCR: (1) whether coverage for the same or a similar service or treatment is available to individuals outside of that protected class; (2) whether it is available to those with different health conditions; (3) the reasons for any differences in coverage; and (4) whether there is "a neutral, nondiscriminatory reason for the denial or limitation that is not a pretext for discrimination."<sup>300</sup> Second, the courts and agencies can then consider other affirmative defenses, such as whether it is truly a fundamental change to a program and whether the change poses an undue hardship to the entity.<sup>301</sup>

Undue hardship could be the check on boundless disparate impact claims, instead of the arbitrary view of the access/content distinction that benefit changes are always fundamental change not required by ADA/Rehab Act.<sup>302</sup> The insurer could no longer simply exclude the disabled; it would now have to make the case for why the benefit is prohibitively expensive.<sup>303</sup> The *Choate* plaintiffs provide an example of what this would look like in health insurance.<sup>304</sup> They requested

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299. Stone, *supra* note 1.

300. Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. 31,375, 31,433 (May 18, 2016) (codified at 45 C.F.R. 92).

301. See Americans with Disabilities Act of 1990, 42 U.S.C. § 12112 (2012); Rehabilitation Act of 1973, 29 U.S.C. § 794 (2012).

302. *Id.*; see BAGENSTOS, *supra* note 9.

303. Crossley makes a similar argument in contemplating a role for ADA suits in managed care in the 1990s. Disability law "does not compel health care decision-makers to arrive at any particular substantive decision . . . ; [w]hat the law does do . . . is compel decision-makers to take persons with disabilities into account in their decisions . . . [making] people with disabilities . . . less likely to find themselves enrolled in a plan that is oblivious to or unaccommodating towards their health care needs." Crossley, *supra* note 1, at 74. Orentlicher has argued for arecognition of reasonable accommodation in health care and has speculated that, in rationing decisions, "a court would likely limit the obligation to accommodate when medical care provided minimal benefit and did so at a high financial cost." Orentlicher, *supra* note 34, at 72.

304. *Alexander v. Choate*, 469 U.S. 287, 291 (1985).

that instead of an annual limit on inpatient days, hospital days be limited based on condition.<sup>305</sup> For example, if a reasonable time to treat a lung infection were three days, then Medicaid could cap the benefit there.<sup>306</sup> Had the Court considered this accommodation, it would ask whether it was reasonable and then whether the entity could accommodate it without undue hardship. The state Medicaid agency would then have to examine their benefits plan to see whether this different model of covering inpatient hospital days was actually more prohibitively expensive than the current cap. In other words, does the cost of covering inpatient days based on medical need far surpass the annual cap for everyone? If it did, then the state Medicaid agency would be free not to grant the accommodation.

Reasonable accommodation would not mean that the disabled have all of their health care needs met.<sup>307</sup> But it would allow for an important shift in the dialogue. In requiring reasonable accommodation, the courts would not necessarily remove the ability of insurers to engage in some rational economic conduct.<sup>308</sup> Instead, it would force insurers to have to consider why their conduct is economically rational and whether they can better meet the needs of the disabled.<sup>309</sup> Ultimately, there may be some additional expense stemming from reasonable accommodation in health benefits. However, Professor Bagenstos argues this to be a fair outcome, as we should no more tolerate rational economic discrimination than animus-based discrimination.<sup>310</sup> If our true goal is to reduce subordination of the disabled, it matters not if someone subordinates you because they dislike you or because it's economically beneficial; the outcome is the same either way in that you are still subordinated.<sup>311</sup> And this is particularly true where we cannot always deduce what is rational discrimination.<sup>312</sup> Discrimination on the basis of disability is frequently presumed as economically rational when it would not be viewed the same for race or sex.<sup>313</sup>

More, recognizing reasonable accommodation in health insurance benefit design would force insurers to have to consider the disabled in

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305. *Id.*

306. *Id.*

307. *Id.* at 288.

308. BAGENSTOS, *supra* note 9.

309. *Id.*

310. Bagenstos, *supra* note 191.

311. Bagenstos bolsters his argument by raising the question of why. If animus-based discrimination were our only concern, would we narrow antidiscrimination law to protected class? If it were animus-based dislike we disapproved of, we would forbid it against all types of people. But instead, we focus on protected groups because civil rights law ultimately seeks to attack subordination, not animus-based hatred alone. *Id.*

312. *Id.*

313. *Id.*

their health insurance designs.<sup>314</sup> There is nothing natural about our health insurance system having been designed to better meet the needs of the healthy than the sick.<sup>315</sup> Instead, it is the result of a system that favored the nondisabled in its policies, just as in other settings.<sup>316</sup> Rationing may be inevitable, but rationing on the basis of sickness or disability is not.<sup>317</sup> As Professor Stone importantly wrote, our society made a political choice when it created a health care financing system that put financial burdens on the individual, instead of on the collective.<sup>318</sup> Our health care financing system, like so much of our infrastructure, was built without considering the needs of the disabled, or with a mind toward avoiding their greater needs in favor of a majority.<sup>319</sup> Accommodating the disabled's needs in health insurance, though, would likely mean better health insurance benefits for all, as is so often the case when the world is improved through reasonable accommodation.<sup>320</sup>

A more generous vision of civil rights laws for the disabled would allow section 1557 to have a single standard in how it handles discrimination in health care, regardless of protected class. Otherwise, only the disabled will be limited in their ability to challenge health care benefit discrimination. Where protected classes have had different standards under section 1557 (for example, in whether they could allow private causes of action for disparate impact), DHHS/OCR has

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314. BAGENSTOS, *supra* note 9.

315. See Orentlicher, *supra* note 34, at 67 (arguing that “there is nothing ‘natural’ or ineluctable about the fact that most aspects of socio-political organization respond primarily to the needs of persons without disabilities . . . . Social norms develop not because they are pre-ordained, but because they serve the needs of social groups that are dominant either in numbers or power”).

316. As Professor McCluskey explains:

In a social historical context in which unequal treatment of a particular identity becomes systematically and pervasively entrenched in institutions, culture, and policies, it is logical to expect that inequality on the basis of such an identity would come to appear natural, rational, and neutral . . . . [I]f a person with paraplegia is excluded from a public bus with steps . . . [j]udgments about whether that person is “really” different from people who can climb up bus steps depend on what we consider the substantive purpose of the bus: transportation for the public, or transportation for members of the public who can climb steps? Determining whether the exclusion at issue is neutral . . . or biased . . . depends . . . on substantive moral and political decisions about whether buses should normally and naturally be designed for entrance via steps rather than by ramps or lifts.

McCluskey, *supra* note 128, at 114–16.

317. Indeed, many countries call their health insurance “sickness insurance” because they recognize that their primary consumer ought to be the sick, and not the healthy. Deborah Stone, *Protect the Sick: Health Insurance Reform in One Easy Lesson*, 36 J.L. MED. & ETHICS 652, 652 (2008).

318. Stone, *supra* note 1.

319. Bagenstos, *supra* note 191; Orentlicher, *supra* note 34, at 67.

320. Satz, *supra* note 202.

unified the standard and has chosen the more generous standard. A single standard that treats all equally (and lifts the bar where one group is less protected) seems to be in line with how DHHS/OCR has handled disparate impact and section 1557.<sup>321</sup> Section 1557's regulations have broadened private actions in disparate impact for more groups than was previously allowed,<sup>322</sup> and have newly extended protections in health care to gender and sex discrimination.<sup>323</sup> It also seems in line with Congress's intent, given that it collectively treated the four protected classifications (race, sex, age, and disability) as on equal footing with respect to health care when it crafted section 1557. Disability antidiscrimination law has long permitted litigation on health-specific discrimination and disparate impact,<sup>324</sup> and addressing the access/content distinction in favor of the disabled reflects a broader effort to fully make use of civil rights in combating health care discrimination.

At the time of writing this, the future of health care in the United States is uncertain. The ACA, and perhaps section 1557 and its attending regulations, face possible repeal or alteration in the face of new presidential, congressional, and agency leadership. Certainly some of the specific arguments in this Article would need to be altered were there to be significant sea change in how our health care system is financed and regulated. Nonetheless, this Article raises broader themes and arguments, that stand apart from the ACA and section 1557, that should still lead agencies and the courts to question the merits of the access/content distinction and to consider its resulting harms. First, despite the various iterations that our health care system may face in the decades to come, *Choate* and the access/content distinction is an over thirty-year-old precedent. In some cases, this leads courts to more strongly guard the precedent, but the holding and the reasoning behind this case are heavily outdated, given how broadly our health care system has changed in those years. Second, whether the ACA or another law stands in the near future, there does seem to be a critical political and public shift in social policy that may withstand any reforms—specifically, there appears to be increasing agreement that health-based discrimination in health insurance is unacceptable. Given that, the access/content distinction arbitrarily fore-

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321. See *supra* note 222 and accompanying text. Note that DHHS/OCR had the choice, where there were incompatible standards, to simply let the different protected classes have different standards. Instead, they sought to unify and ensure that race was treated equally compared with the other groups. The same could be true here—the disabled should equally be permitted to challenge benefit design, just like other protected classes.

322. See *supra* note 222 and accompanying text.

323. 45 C.F.R. § 92.206 (2016).

324. Recall that *Alexander v. Choate*, 469 U.S. 287 (1985), also stands for permitting disparate impact in disability suits, even though it later limited their scope.

closes an evaluation of whether health insurers discriminate against the disabled in health benefits. This is a necessary matter to consider if we seek a broader goal of considering equitable health care financing for those with serious health needs. With these matters in mind, agencies who seek to continue to regulate the health care industry and courts hearing disability antidiscrimination suits should be critical of the access/content divide, asking whether it furthers the goal of better health and more equitable financing for the disabled and whether it is a necessary and fair means of achieving what appears to be its broader aims of controlling the rising cost of health care, given that undue burden would remain an affirmative defense for insurers even if the access/content distinction was eliminated.

Ultimately, a vision of health care financing in which the sick pay their own way has eroded in recent years. There is no reason why civil rights law for the disabled cannot come along with this movement by moving past the access/content distinction and fully considering discrimination in health benefits for the disabled.